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ABSTRACT

This document summarizes a conference sponsored by the Montana University Affiliated Rural Institute on Disabilities (Rural Institute). The Rural Institute is a center for interdisciplinary, multi-organizational research, service, and training projects aimed toward improving the lives of persons with disabilities who live, work, and recreate in rural areas. Twenty-six speakers made presentations on exemplary programs in five topic areas: (1) building linkages, collaboration, and networks; (2) integrating training with services; (3) support systems from the community, professionals, and peers; (4) improving accessibility by using interactive television and improving transportation and facilities in public buildings; and (5) innovative rural interpretations of disability laws and policies. This document contains transcripts of the conference presentations, grouped by topic area and followed by the "common threads" for each area, i.e., summaries of the comments made during each plenary session. A "Rural Disability Services Network" initial directory, citing programs from various states is included. The appendices include recommendations for consumer advocacy involvement and a summary of the Americans with Disabilities Act technical assistance grants and coordination contracts awarded through the National Institute on Disability and Rehabilitation Research. (LP)

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COMMON THREADS

Weaving Together Rural Resources for People with Disabilities

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PROCEEDINGS

Common Threads Conference
September 15-17, 1991
Missoula, Montana

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Montana University Affiliated Rural Institute on Disabilities

The University of Montana, Missoula, Montana

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COMMON THREADS

Weaving Together Rural Resources for People with Disabilities

Proceedings of the 1991 Common Threads Conference

Kathy Dwyer, Editor
Diana Spas, Editor
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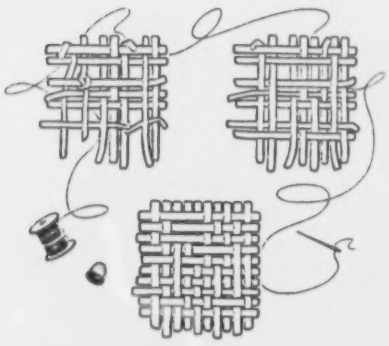

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The University of Montana, Missoula, Montana 59812

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Montana University Affiliated
RURAL INSTITUTE ON DISABILITIES

The Montana University Affiliated Rural Institute on Disabilities (Rural Institute) is a center for interdisciplinary, multi-organizational research, service and training projects. The primary mission of the Rural Institute is to **improve the lives of persons with disabilities who live, work and recreate in rural America.**

In 1978, the federal Administration on Developmental Disabilities (ADD) acknowledged the need for a University Affiliated Program in Montana. ADD granted funding and the Rural Institute began operation on the University of Montana campus in 1979. The Research and Training Center on Rural Rehabilitation Services (RTC:Rural) was established within the Rural Institute in 1987, with funds from the U.S. Department of Education's National Institute on Disability and Rehabilitation Research (NIDRR). Throughout its history, the Rural Institute has clarified its mission, steadily increased the number of its programs and expanded the scope of its activities to a national scale.

The Rural Institute has grown in many ways, from the numbers of staff and projects to the size of its office space. Funding has increased tenfold: from **$126,000** in fiscal year 1979 to over **$2.5** million in fiscal year 1991. The Rural Institute now generates an **additional $12 for every $1 of core funding** received from the Administration on Developmental Disabilities.

The Rural Institute responds to local, regional and national needs by:

- conducting **research, service and training activities** with health, education and welfare agencies, as well as private organizations that focus on rural needs,
- providing **technical assistance** to organizations and agencies in rural areas, and
- collecting, coordinating, and disseminating **information** related to rural disability issues.

These service, training, technical assistance, research and information dissemination activities:

- help people with disabilities in rural areas find **quality social and educational services, and health care,**
- increase the quantity and quality of **disability service professionals and care providers in rural settings,**
- discover and develop **state-of-the-art approaches** to meet the challenges of living with a disability in rural areas; and
- provide **information about rural issues** to the public and professionals.

The ultimate aim of the Rural Institute is to improve the well-being, self-sufficiency, and productivity of Americans with disabilities in rural areas.

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INTRODUCTION

On September 15-17, 1991, the Montana University Affiliated Rural Institute on Disabilities sponsored the conference **"Common Threads: Weaving Together Rural Resources for People with Disabilities"** in Missoula, Montana. The goal was to bring together people knowledgeable about disability services in rural areas, and to help them share their experiences, challenges, and solutions: their "common threads."

Speakers made presentations on exemplary programs in five topic areas:

Building Linkages, Collaboration, Networks
Integrating Training with Services
Support Systems
Accessibility
Innovative Rural Interpretations of Disability Laws and Policies

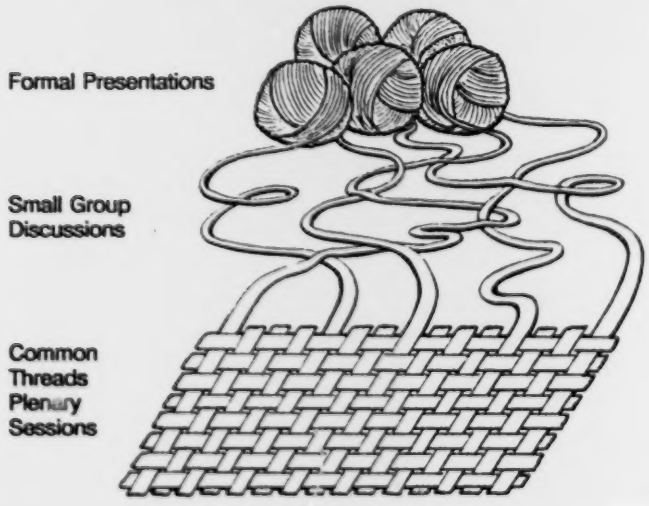
After the presentations in each topic area, conference participants adjourned to small group sessions, where facilitators guided the discussion to highlight the ways that participants' programs had responded to the challenge of the topic area. Participants were encouraged to share experiences, expertise, and problems. The facilitators kept notes on flipcharts, then distilled each one-hour discussion into a single sheet of "common threads."

Each participant was also provided with a "do-it-yourself conference participant's resource directory." As the participant rotated through various small group sessions, she or he could enter information on this form in a space next to each participant's name: detailing areas of expertise, type of program, innovative techniques, etc. This helped participants get to know each other better and encouraged networking.

The groups reassembled for morning and afternoon Common Threads plenary sessions, in which all the facilitators summarized the small groups' contributions--followed by a general discussion of the topic area by the entire group. The diagram below illustrates the overall flow of the conference: from the initial presentations, through the small group discussions, to the plenary sessions.

Programmatic Flow at the 1991 Common Threads Conference

(a playful representation)



This document contains transcripts of the presenters' talks, grouped by topic area and followed by the "common threads" for each area, i.e., summaries of the comments made during each plenary session. Comments are grouped according to subject matter, but not in order of mention or importance. They are all equally important--though "common threads" which were voiced the most frequently are printed in bold-face type. These Common Threads plenary sessions elicited positive, proactive statements comprising the collective wisdom of some very innovative rural disability programs, and we are pleased to be able to share that wisdom with you.

KEYNOTE

FROM COMMON THREADS TO A NETWORK

Jim de Jong, Executive Director
Coalition of Citizens with Disabilitiies in Illinios

The provision of effective comprehensive services to citizens with disabilities requires adequate resources; human and fiscal. It requires the involvement and understanding of the population we serve. It requires an understanding of the unique and specific characteristics of the locales we work and live in and the networks which operate in our communities. We must identify our common threads and weave them into a responsive and effective network.

Given all the components required to successfully interact in our jobs, our vision must be clear, concise and comprehensive. What has been espoused at this conference is our common vision of the full integration of persons with disabilities in all aspects of life, work, recreation, school, religions and community activities. To successfully meet our goals we must understand the society we wish to integrate and the forces which drive our society. These forces are capitalistic and democratically driven. Therefore, we must understand and interact in these arenas. We must become politically aware and active to create opportunity and adequate resources for citizens with disabilities to utilize iii the fulfillment of their maximum independence and productivity.

We have shown clearly at this conference the need to be involved in networks, formal and informal, and I contend we are experts at maximizing our resources, but we have historically shied away from politics. This must change today, You cannot be effective in service delivery or social policy change without political action. For it is politicians who determine resource allocations or put in basic terms, it is they who distribute your tax dollar. If we do not speak up or weave our work into the political arena, then we cannot complain that our issues are ignored.

To actively and effectively affect the political arena we must first get our own act together. We must involve all the players in our field, the dedicated counselors, effective administrators, and service providers involved in the complete spectrum from the medical rehabilitation field to the supported employment job coach and all others. Most of all, and primarily, we must empower and involve citizens with disabilities, their families and friends. If we were to place all these players in a common arena, we must represent at least 25% of the entire population in America.

Clearly, we have the numbers to affect political responsiveness, but we have not consistently recognized our potential political power. This potential impact upon the American political landscape is valid to rural areas as well as urban. In fact, as we have learned today the impact on the rural political landscape is available to us through the networks we have defined and articulated in our areas of the country. The church, the local cafe breakfast meeting, the various animal clubs (Lions, Moose, Elks, etc.) and our rehabilitation networks.

We must dedicate ourselves, whether an office manager in our field or the consumer of service to get politically involved and influence the social consciousness of America and the resultant resource allocation of our tax dollars to create opportunity for citizens to be productive as personally possible.

If we break down the word **POWER**, it can be our guiding principle to action.

P - **Pride** in our profession and population of people we are working to assist. Remember we enter this field not for the financial rewards, but to make America a better place for all its citizens.

O - **Outreach** must continually occur to under-represented groups and to potential allies (i.e. senior citizens).

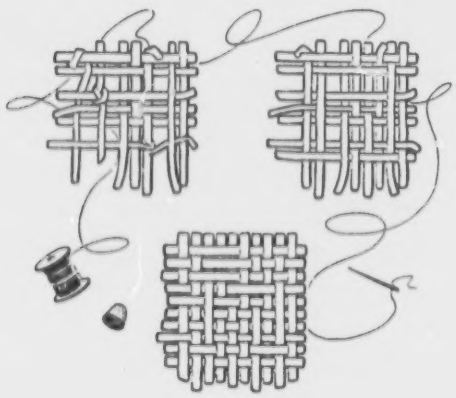
W - **Wisdom** to understand the society we wish to integrate, which means participatory democratic action.

E - **Energy** to attend town meetings and political activities so our presence and views are felt and heard consistently.

R - **Respect** for one another and the unique and individual talents we bring to our political movement, There is not one easy way to influence the political arena. It takes diverse efforts from attending the same church as a local politician, to writing letters to legislators, to testimonies in Congress. Advocates should bring diverse talents to our cause since it is a diverse multi-cultural world we wish to integrate and make accepting.

When we put all these characteristics together toward our common vision we will have **POWER** to create an accessible, acceptable world of opportunity for citizens with disabilities and a better America. The **POWER** is yours to have and to use. We have the threads of potential, we must now weave them into a network of reality.

For more information contact the ROBAC Program, University of Missouri at Columbia, 401 East Locust Street, Columbia, MO 65201, (314) 882-3807 or (314) 882-1727 FAX.



BUILDING LINKAGES COLLABORATION NETWORKS

INTERAGENCY COLLABORATION FOR TRANSITION SERVICES FOR YOUTH WITH DISABILITIES IN RURAL AREAS

Patricia Wallisch, State Coordinator for Transition (Presenter)

Transition services for youth with disabilities in rural areas are often nonexistent or, at best, hard to access. Rural disabled youth have an even harder time than their urban counterparts seeking jobs, reliable transportation to and from work, appropriate leisure time activities, and suitable independent living resources. Many of these young people simply graduate from high school and then spend the rest of their lives at home with their families. Their potential is untapped. Generally, they are unhappy with the quality of their lives.

In Aberdeen, South Dakota, and the surrounding rural areas, many of these problems are being solved by the Transition to Adulthood Project, funded two years ago by the State of South Dakota through a Federal Grant. The project was piloted in the Aberdeen area. It confirmed that many of these problems existed. But if the project was going to succeed, there had to be a collaborative effort in the community to support plans for achieving the goals of maximum independence and a quality life style for the disabled population it intended to serve.

Collaboration with community organizations, government agencies, school personnel, employers, and parents in and around Aberdeen brought solutions to many of these problems. This collaborative effort made the Transition Project in Aberdeen a model program for the state to follow. Dissemination of the project is now being started throughout the state, and its success has been attributed to the combined efforts of people working together for the common purpose.

It is important to understand the roles played by these organizations and how they contributed to the success of the project. The organizations can be essentially divided into five areas: community organization, government agencies, school personnel, employers, and parents.

Community Agencies

The Adjustment Training Center, Aberdeen Parks and Recreation Department and Northeast Mental Health have played an active role in transition planning.

The Adjustment Training Center has attended transition meetings for students in high school. It has responded on a number of occasions in the areas of testing and vocational evaluations for disabled students. Although the idea is to plan for individuals in the least restrictive environment, in some cases students are entering the Adjustment Training Center for work experience in a sheltered environment after high school.

The Park and Recreation Department in Aberdeen has been especially active with the school district in addressing leisure-time activities for the disabled population. The Special Needs Consortium was formed with the school district, parents, and Park and Recreation officials to plan recreational opportunities. Activities like swimming lessons, open gym, dances, and cross country skiing were planned by the Consortium.

The Northeast Mental Health Agency has been working with the Transition Project to do vocational evaluations in the work environment. Through a grant, the agency is currently funding a program whereby they will evaluate a student's work potential through a series of job tryouts in the community during a two-week period.

Government Agencies

Vocational Rehabilitation and Job Service have both contributed expertise in job-related areas. Vocational Rehabilitation Counselors are now attending all senior and junior year students' transition meetings. They are getting an earlier start on adult planning and lending their knowledge to the Transition Planning Team when necessary.

Job Service has become actively involved with students through the STEP Program and Summer Youth Employment. They are also providing training for teachers who are using the STEP curriculum. Classroom teachers are not alone in their pursuit of jobs for students facing transition. These agencies are playing a vital role.

School Personnel

Both administrators and teachers have worked cooperatively within the Transition Project to develop Transition Plans for high school and junior high students. The Administration has supported in-service for their teachers and staff on transition issues, and they have encouraged them to attend a Transition Course given at Northern State University. In this course teachers and prospective teachers are learning how to teach a functional curriculum so necessary for success in adult life. They leave the university ready to develop transition plans.

Employers

The Transition Project and the collaborative agencies have begun to educate employers about students with disabilities. Employers are now more willing than ever to hire disabled students because of the cooperative efforts. Employers can feel secure about hiring the disabled in our community because of the support that is being given to both the employer and student.

This spring an Employer Appreciation Tea was held. The mayor presented each employer with a certificate of appreciation. The event was well attended and viewed as a total cooperative effort.

Parents

A parent support group has been established by the Transition Project. A day in-service was given to parents about Transition. Very positive results have been seen with parents by both the support group and in-service. Parents are able to intelligently discuss transition needs and make decisions about their children's future. They have become valuable members of the team, and they are helping educate the community.

These collaborative efforts have resulted in the development of several committees working together for the benefit of disabled students. The Interagency Task Force is made up of representatives from all agencies, the transition team, school personnel, parents, and students. The Transition Council has brought together the Administration from the agencies and schools. A transportation committee was formed by several community leaders. Along with Northern State University it is looking at the problem of transportation for the disabled.

None of these groups can achieve the goals necessary for successful transition by themselves. Through cooperation and communication, a rural community like Aberdeen, South Dakota, can improve the quality of life for rural disabled youth.

For more information contact the Transition to Adulthood Project, Northern State University, 16 13th Avenue NW, Aberdeen, SD 57401, (605) 225-0037.

RURAL VOCATIONAL REHABILITATION IN THE TRIBAL SETTING

Joe Kelley, Project Director (Presenter)

The Kodiak Area Native Association Vocational Rehabilitation Project (KANA VR) is one of 14 Native American groups receiving funding from the Department of Education/Rehabilitation Service Administration. KANA VR provides vocational rehabilitation services to Native American individuals living on reservations or within the boundaries of an Alaskan Native Corporation. The KANA VR Project provides rehabilitation services to Native people living on Kodiak Island.

Kodiak Island is the largest island in an archipelago bounded by the Shelikof Strait and the Gulf of Alaska, southeast of Anchorage, Alaska. This island group of 5,000 square miles contains approximately 900 miles of coastline. A total of approximately 4,000 Alaska Natives live in the City of Kodiak or one of the six coastal villages, scattered around the Island. Kodiak's six villages are: Akhiok, Karluk, Larsen Bay, Old Harbor, Ouzinkie, and Port Lions.

Alutiiq was, and continues to a diminished degree, to be the Native language of Kodiak Island. Abundant marine resources have traditionally been Kodiak's economic foundation. Those marine resources have supported the Kodiak Native culture through at least 7,000 years of continuous habitation.

Kodiak Island is located 255 air miles southeast of Anchorage, Alaska. Anchorage, a city of 250,000, is the nearest urban area. Kodiak Island is a mountainous island approximately 100 miles long and 30 miles wide. The six Alutiiq villages located on Kodiak Island range in population from 75 to 400. The population on Kodiak Island is 16,000, which includes a Coast Guard facility.

The only transportation available from Kodiak to the mainland is airplane, ferry, or container ship. All air transportation goes through Anchorage, which functions as a transportation hub for our part of the state. Kodiak villages are served only by air (single engine) and Kodiak's transportation hub is Kodiak City. Air travel is very weather dependant as village air strips have no instrument assistance. Kodiak has a fairly moderate climate, but has many days of strong winds, rain, fog, snow, and icing conditions (October through April) which make flying hazardous.

Medical specialties such as Orthopedics, Neurology, ENT, Ophthalmology, and Psychiatry are not available on Kodiak. Specialists can only be seen by traveling to Anchorage or waiting for their monthly visits to Kodiak. The Kodiak Community College provides some BA work, however, technical training other than general clerical is only available off island.

The primary business in Kodiak is fishing, support service for the fishing industry, and support services for the Coast Guard Base.

Approximately 25 years ago, KANA was formed as a Native American contractor to the Bureau of Indian Affairs, Indian Health Service, and various other state and federal agencies. KANA's primary goal was the provision of health and social services. However, in the past 25 years, KANA has expanded to provide various Educational programs, Indian Child Welfare, Alcohol Outreach, Tribal Operations, Culture and Heritage Services, and Vocational Rehabilitation services. KANA employs approximately 100 people and provides services from a central location in Kodiak as well as a number of employees in each village. The key providers in the village setting are Health Aides, Community Health Representatives, Village Public Safety Officers, and Suicide Prevention Workers. To accomplish the goal of providing comprehensive Vocational Rehabilitation services within the Tribal setting, KANA VR must maintain a significant number of linkages.

For those who may not be familiar with Vocational Rehabilitation, it is a federal program administered under the Rehabilitation Service Administration (RSA) in Washington, D.C. and is generally carried out by each state. However, in 1986 Congress passed an amendment to the

Rehabilitation Act of 1973 which indicated that a Native American tribe could apply for and receive their own monies directly from RSA to provide vocational rehabilitation services on their reservations. The reason for this amendment was the fact that due to the rural nature of most reservations or Alaskan Native Corporations, state agencies could not or would not provide adequate services for Native American clients. Subsequent to this amendment, the Navajo Nation and others of us have applied for and received monies to establish our own vocational rehabilitation programs.

Whether State Vocational Rehabilitation agencies or Section 130 Projects by Native American Tribal Groups, vocational rehabilitation is basically the same. Our goal is to provide comprehensive vocational rehabilitation services that will enable people with disabilities to maximize their employability, independence, and integration into the work place and the community.

As indicated, our programs are generally the same as far as eligibility criteria, however, there are some differences. The federal program guidelines are quite broad but typically each state redefines those federal guidelines within the context of its own needs. KANA VR has also done this, but in a way to deal more effectively and give our people greater opportunities to receive services.

I would like to talk about linkages that we have established to assist us in providing Vocational Rehabilitation services to Alaska Native or American Indian people residing within the boundaries of our region. In thinking about linkages, KANA VR really has to function and establish linkages on at least five levels. These five levels are:

1. Village Level
2. In-House/KANA Service Unit
3. Community Level
4. Statewide Level
5. National Level

In reality, KANA VR cannot function adequately to serve constituents without functioning on all five levels.

Village Level

To provide the day to day services necessary within our region the KANA VR staff must work closely with people in each of the six villages on Kodiak Island. Within each village there is a Village Response Team made up of the Community Health Aide, Community Health Representative, Village Public Safety Officer, and various other professionals/paraprofessionals which may be working within the village at that time. Members of this team provide referrals to KANA VR and provision of services directly to clients residing in the villages, such as medical services, counseling services, assistance in completion of paperwork, etc. Also, each village has a school, usually K-12. It is very important to work with the individual school principal or staff to receive referrals and to provide services to students who may qualify for Vocational Rehabilitation services. Finally, it is important to work with different community leaders and officials who may represent the Tribal Council, the Village Corporation, or the city entity which exist in each village. These individuals can also provide referrals and placement potential for clients living in the village.

KANA Service Unit

Within the KANA service unit, KANA VR works closely with the various other departments such as:

- Medical, which assists us through the provision of referrals, physical examinations, medical services, medical consultation, and various other medically related services.
- Dental, as they from time to time provide referrals, consultation, and restorative services to clients.
- Alcohol Outreach provides referrals, screening and counseling services along with consultation in the development of many of our Vocational Rehabilitation plans.
- Social Services provides supportive services to clients while they are receiving services from us.

- Education works with us to assist in mutual development of plans for educational and training needs. In addition they are a valuable resource for funding assistance.

- Culture and Heritage assist us to assure cultural appropriateness in developing our VR project.

Community Level

As KANA functions within the larger community of Kodiak City, we also interface with a number of local agencies or businesses which are critical for the provision of rehabilitation services. Some of the local linkages are:

- The Kodiak Branch of State Vocational Rehabilitation which provides referral and consultation. The local State VR representative is a valuable resource as far as consultation concerning general vocational rehabilitation and also a critical link in carrying out a collaborative agreement which I will discuss later.

- Kodiak Island Mental Health provides not only referral, evaluation, and treatment, but has generously provided us with Mental Health consultation on a weekly basis to staff cases at no cost to KANA VR.

- Kodiak Island Borough Schools is an important resource in referring youth who may qualify for our program and providing a good environment within which to interact with youth early on in their lives.

- Kodiak Council on Alcoholism provides referral services, screening, and treatment. As alcoholism is one of our primary disabling factors, their services along with our in-house alcohol outreach program are extremely critical in the provision of vocational rehabilitation services.

- Finally, a very critical link in the chain are local Kodiak businesses who ultimately will employ many of the people we work with.

State Level

The next level of networking is the statewide level. On the statewide level some very exciting things have occurred. While we do interface with the State Arts Council and various other entities, I am most excited about the interaction with the State of Alaska, Division of Vocational Rehabilitation. In June of this year, after several months of interaction with the State VR Director, Keith Anderson, a collaborative agreement was drawn up between KANA VR and the State DVR. The exciting thing about this agreement is that I believe it's one of the most far reaching collaborative agreements between any Tribal group and State VR agency. The primary attraction of this agreement is that it sets up a close working relationship which allows the KANA Vocational Rehabilitation Program to function autonomously yet receive the benefit of being closely linked with State VR and function very much like a state branch office. KANA VR will use a similar statistical accounting system, a similar case file and recording system which can easily be transferred between KANA and the state agency. According to this agreement if KANA clients need to leave our region for services, the case can be transferred to the appropriate state office and continue receiving VR services through the state system without having to have their eligibility or plan reviewed. This agreement essentially allows for the state to spend State VR dollars to serve KANA clients while they are working with the State VR counselor. This is a significant benefit to our clients who no longer have to be made eligible for the state program or have a separate plan developed. Also, under the new agreement KANA VR will participate as a member of the State VR Advisory Council.

National Level

KANA VR also must interact on the national level with the Department of Education and with the Rehabilitation Services Administration to compete for funding, receive technical assistance and receive oversight. National oversight for the Section 130 VR Projects is provided out of Washington D.C. and the regional office in Seattle.

As indicated earlier, many levels of linkages

are required to function. However, this dynamic exchange of ideas and information provides a very fertile environment within which to function. I feel that tribal VR clients can receive the best of both worlds, if 130 VR Projects are willing to rise to the challenge of the many levels of linkages which are required to function successfully.

For more information contact the Kodiak Area Native Association KANA Vocational Rehabilitation, 402 Center Avenue, Kodiak, AK 99615, (907) 486-5725, (907) 486-2763 FAX.

COMMUNITY OUTREACH PROGRAM

Charles N. Schroeder, Executive Director (Presenter)
Marie Rose, Director of Adult Services

The aging people of Putnam County, Indiana, are active in their communities, integrated and interacting as the result of a collaborative effort of local aging services agencies.

The Community Outreach Program originated through Putnam County Comprehensive Services, Inc. (P.C.C.S.), a not-for-profit agency serving citizens with disabilities in the rural counties of West-Central Indiana. Programs serving the adult population are educationally and/or vocationally oriented.

In January of 1989, Putnam County Comprehensive Services, Inc., identified a group of citizens with disabilities who were approaching retirement age. Through the normal process of aging, some of these individuals were developing health problems and becoming incapable of working a regular day.

Finding alternative services for this aging population became one of the annual objectives of the adult program staff. Staff began investigating programs serving the aging citizens of Putnam County. They called health providers, social workers, community representatives and state funding resources. Four areas of concern surfaced:

1. There were no available services for the aging adult with a disability who wanted little or no vocational programming.

2. With few exceptions, once an individual with or without a disabling condition entered a nursing home, community contacts diminished.

3. Aging individuals who resided with a family member had little to no opportunity for stimulation outside of the home. In addition, families caring for an elderly relative had limited opportunity for relief.

4. Individuals without private transportation were unable to participate in community events or activities.

It was clearly necessary to improve the quality of life for these people, and assure them both the freedom of choice and the independence of which they were capable.

With neither funding nor available services, staff discussed the issues:

- needs of individuals within all four areas of concern
- methods of integrating these individuals into the community
- services available in the community
- how present services could be expanded
- better personnel use.

Staff met to discuss these issues with nursing home and community resources personnel serving the elderly. They reviewed the activities provided by each nursing home and agency. Although each home provided a wide range of activities, there were various problems such as small groups, residents with widely varying functional levels, lack of transportation and limited staff time.

A strategy evolved: one Activity Director

could provide an activity for individuals from the other organizations, if P.C.C.S. could provide transportation. This would promote integration and community involvement for those participating and simultaneously allow the other Activity Directors more time to serve the remaining residents.

The time contributed by the Activity Directors would be used to sponsor one or more activities each month. These activities were open to all individuals over the age of fifty-four and included residents from each nursing home, as well as individuals with disabilities and other citizens from the community.

A partnership developed. Each nursing home contributed a minimum of ten percent (10%) of their Activity Director's time to the project. P.C.C.S. contributed the use of an existing vehicle and driver. (Transportation provided for extended trips is paid on a usage basis by each organization. Transportation is also available outside of normal work hours for private leasing. These monies supplement the overall transportation costs while providing a needed service to organizations without a means of transportation.)

Riding a wave of enthusiasm, Activity Directors met the following week and one week later the project started.

The Community Outreach Program generates no additional costs. The program coordinates and expands the non-vocational services of P.C.C.S. and the local nursing homes. Activity Directors at each nursing home and the Transportation Coordinator of P.C.C.S. provide approximately fifteen integrated activities each month.

The program provides a wide variety of activities both in and outside of the nursing home: outings, shopping trips, visits to other nursing homes, fishing and boating trips, tours of new local industry, special events and other activities. McDonald's Restaurant, the Moose Lodge, city and state parks, and the Senior Center provide space for bingo and other social events.

Although each organization is funded individually, the nursing homes and P.C.C.S. are required to have a written Individual Plan for each person involved in their program(s). The Individual Plan(s) include the strengths, abilities, limitations and needs of each individual. The Activity Directors determine who will participate in each activity through this plan.

Although the program is currently not operating as part of a curriculum, each month the "partnership" meets to develop a monthly schedule of activities. The schedule is determined by: the goals of the Individual Plan(s), available staff time, seasonal activities, community events, and individual preference.

Monthly meetings develop the schedule, review individual progress, resolve problems, share ideas, interpret standards and strengthen the network/training partnership. The Activity Directors have higher morale and an improved job retention rate as a result.

Approximately seventy-five individuals have participated in the program. Although this cooperative venture is young, it has already shown many benefits:

- Participants with and without disabilities are integrated;
- Participants are more interested in the community;
- Participants who were once isolated have better access to the community through transportation services;
- Participants have a broader knowledge of community resources;
- The quality of programs has improved, resulting in increased referrals to nursing homes and P.C.C.S.;
- Participants from the community are becoming more involved in the social activities provided by the nursing homes and the community;
- Community resources such as the Senior Center, McDonald's, and the parks are used more;

- Participants are more independent;
- Participants help develop their Individual Plans and give input to community leaders;
- Participants are more functional;
- Surveyors are pleased that the organization is actively pursuing and providing integration;
- The morale and motivation of participants and staff is greatly improved;
- An innovative and creative network of service providers now exits.

This program is limited, however, by the lack of funds to fully develop and to expand it throughout the service area. The project staff continue to pursue funding sources, especially for trans-portation services. It is anticipated that a sliding fee scale may be necessary for community participants to offset the costs of supplies and transportation.

This program can be easily duplicated in any community which has existing services for the aging population. It is more economical to use existing services by cooperating with other organizations than it is to initiate a new service.

The following is a list of steps to develop and implement the Community Outreach Program:

1. Identify organizations that provide services to individuals with similar needs, such as family support groups, organizations serving individuals with disabilities, nursing home facilities, churches, and community resources;

2. Meet over lunch; invite the administrators, as well as direct providers of the services;

3. Discuss issues and develop a list of "common needs";

4. Introduce the strategy;

5. Get a commitment from the Administrator or CEO of each organization;

6. Set up a time for the direct providers, such as the Activity Directors or Social Workers, to meet on a regular basis;

7. Discuss the specific expertise of each provider;

8. For the first month or so, develop a simple schedule of three or four activities using this expertise;

9. Implement the schedule, discuss problem areas and make adjustments as needed;

10. Expand the program by developing a schedule that provides more activities to more participants and uses the creativity of the providers;

11. Keep activities age appropriate;

12. Monitor and modify the program as needed;

13. Encourage the group to share problems and solutions openly;

14. Advertise and seek funding to expand.

This program is best summarized by Margaret, a program participant: "Sadie and I lived next door to one another all of our lives. We were separated when she moved into one nursing home and I to another. Except for a few visits when my daughter came, I never got to see Sadie. I was so tired of looking at the same people. Now, through this program Sadie and I get to visit every week, I get a chance to see how Greencastle is changing, I get to do different things and I am happier. I no longer feel like I am too old to enjoy life, but that I am an older person who can go out and enjoy things around me. I may be too old to walk places, but because of this program I am still able to get out."

For more information contact Putnam County Comprehensive Services, Inc., 630 Tennessee Street, Greencastle, IN 46135 or call (317) 653-9763.

EMPOWERMENT AND AGING

Anne Cook, Project Director (Presenter)

Stipend Based Opportunities for Low Income Elderly: Strategies for Rural Programming

The Foster Grandparent Program was established on a national level in 1965, and the Senior Companion Program followed in 1975. Both programs respond to the poverty and isolation commonly experienced by low income elderly. The programs enroll income eligible senior citizens and provide hourly, tax-free stipends in exchange for a twenty-hour per week work commitment. In Missoula, the Foster Grandparent Program has been operational for nearly 20 years. The grant for the Missoula Senior Companion Program was awarded seven years ago. The competition for these Action grants is significant and the funding availability has not kept pace with the developing need. It is increasingly difficult for local communities to secure Action grants, and considerable local financial support is often needed to meet the demand for services. We are fortunate in Missoula, to have secured ongoing federal Action grants as well as federal Action demonstration and challenge grants. The Missoula Foster Grandparent Program was one of 25 projects selected nationwide, on the basis of outstanding programming, to participate in the 25th anniversary celebration of the program. Local program staff have also designed training and retirement protocols that have been presented at national and regional Action conferences and which are used by projects nationwide.

There have been very significant changes in the aging population since these programs were originally developed. The aging population is much less homogeneous, with more diverse and different needs. Changes are reflected in the results of a systematic analysis of the entry-level characteristics of persons enrolling in the Foster Grandparent Program. This nationwide longitudinal study assessed the age, gender, education and handicapping conditions of newly enrolled participants. The information provides insights into changing patterns within the elderly population, underscores the impact of poverty and clarifies the potential roles of persons with disabilities. Because of the age and poverty restrictions for program inclusion, newly enrolled participants are increasingly older, report more disabilities, have fewer years of formal education and are more often female. One of the most noticeable trends is the significantly increased enrollment of persons with disabilities.

Those changes create new management issues for both the Senior Companion and Foster Grandparent Programs. It is more difficult to maintain a stable corps of trained participants, and recruitment and training of replacements are more time consuming. It is more challenging to arrange support services such as transportation and individualized training. Jobs have to accommodate the needs and skills of persons with more disabilities and less education than the national mean. Retiring program participants and the concomitant loss of stipend dollars is an issue of growing importance. Scarce federal dollars underscore the growing importance of securing local funding in a non-competitive manner. However, in spite of some challenging obstacles, the programs manage to exceed expected service levels and maintain considerable community support. The programs meet those challenges and are able to provide structured, quasi-employment situations by implementing a variety of strategies which are successful in rural areas.

Individualized Training, Placement and Assessment

In order to meet placement and training objectives, individualized job descriptions are created for enrolled participants. In Missoula, Montana, over 75 senior citizens are enrolled in the programs and, through individualized job descriptions, annually provide over 70,000 hours of service to children, homebound elderly or adults with developmental disabilities. Job descriptions are created jointly by the work sites and the program office and are minimally evaluated on a quarterly basis. Mandatory group in-service training is held monthly and

ongoing individualized training is provided. Participating senior citizens are "apprenticed" to key agency personnel so that daily support, supervision and training is possible. The program director maintains close contact with both the senior participants and the supervisory personnel. Regular monitoring, job coaching and reinforcement enhance the likelihood of successful placement. Overall program evaluations are conducted annually and are an integral component of program management.

Networking

Programs such as these demand considerable local financial support and a commitment to the programs' goals and objectives. Commitment is enhanced through systematic involvement in agencies and issues complementary to the programs' objectives. Program staff are involved in various community boards and councils, attend hearings, write support letters on pertinent social issues and maintain ties with diverse university and community contacts. In turn, community members assume roles on program advisory councils. The focus is on "getting the job done" through sharing the power and the information. Financial support, recognition, transportation, training and employee health maintenance are issues of importance to a wider pool of concerned individuals and supporting agencies. The grassroots support for these programs is significant, largely because the programs provide opportunities for intergenerational interaction. That support is particularly critical when dealing with limited economic resources. Funding includes federal Action grants, and financial support from the city, the county and the United Way. In-kind support is generated through a variety of resources.

Management Philosophy

It might be unusual for a non-profit venture to include specific management philosophies as a key strategy. However, in an era when agencies are competing for the time and attention of community contacts, attention to the details of management is important. Timelines are rigorously honored. Agendas for meetings are prepared and mailed well in advance. Agendas are followed and meetings close at the designated time. When community help is requested, the tasks and the timelines are clearly identified verbally and in writing. Trainers meet with program staff prior to training sessions and discuss strategies, possible problems and contingencies. The emphasis is on long-range or strategic planning rather than crisis management. Program staff must understand the organizational structure of affiliated agencies--an important issue when designing appropriate placements for the Foster Grandparents and Senior Companions. Expanding and coordinating the information base empowers both the seniors who participate in the program as well as other key individuals. Choices and options are carefully delineated and decisions made after reasonable consideration. The overall emphasis is on competence, not competition.

In conclusion, these programs illustrate the ability to develop and use the skills of eligible participants when other employment options are unavailable. In a rural setting and with limited financial resources, these programs have been able to expand to meet more needs.

For more information contact Missoula Aging Services, 227 West Front, Missoula, MT, (406) 728-7682.

COOPERATIVE EXTENSION SYSTEM
A NATIONWIDE NETWORK OF RESOURCES

W.E. Field, Professor (Presenter)

The Cooperative Extension System provides a natural, well-established network to disseminate disability-related information to rural and farm (implies ranch, as well) residents with disabilities. In addition, the Extension System has the potential to play a significant role in developing greater public awareness in rural areas concerning disability issues, such as the implications of the ADA. There exists no other resource or educational network in the rural community that is so well organized or respected.

In 1898, the United States Department of Agriculture (USDA) hired an energetic agriculture teacher, Seaman A. Knapp, to help farmers of southern Louisiana raise more rice. His approach was to use demonstration farms to allow local farmers to clearly see for themselves that certain production practices were more productive than others. His motto was: "*What a man hears, he may doubt; What he sees,* he *may possibly doubt, but what he does, he cannot doubt.*"

In 1903, Knapp was re-assigned to help reduce the severe boll weevil damage to Louisiana and Texas cotton. On a 70-acre farm near Terrell, Texas, using funds borrowed from local businessmen, he began to demonstrate practices that were effective at controlling the boll weevil. The demonstration was successful, additional staff were added in 1904, and the concept was taken to other parts of Texas. By the end of the year, Knapp and his agriculture teachers had held approximately 1,000 meetings across the south and convinced over 7,000 farmers to establish demonstration plot. These teachers were called "USDA Agents" from which the present title County Extension Agent comes.

Knapp developed a vision of having an agricultural specialist or "agent" living and working in every county in the United States. These agents would network and have a common mission of improving agricultural production. In 1906 with a one million dollar grant from the General Education Board endowed by J.D. Rockefeller, his dream began with the hiring of the first agents in Texas and Alabama.

During the pre-World War I years, the youth component of Knapp's vision developed from local corn-growing contests and demonstration plots to become the 4-H Club. Formally recognized in 1911, the 4-H Club quickly became the most-visible and best-known of Extension's activities. By 1918, over 500,000 young people were enrolled in 4-H Clubs.

In 1914, the Smith-Lever Act was passed which formally established and partially funded the Cooperative Extension System. It was setup as a formal partnership between local, state and federal agencies with the educational resources coming primarily from the land grant institutions established by the original Morrill Act signed by Lincoln in 1862 and the Agricultural Experiment Stations established by the Hatch Act of 1887. (A second Morrill Act was signed in 1890 adding additional land grant colleges to serve the black population.) By the end of 1918, over 2,400 counties in the United States had agricultural agents and almost 1,800 had Home Demonstration Agents who demonstrated more effective ways of processing and storing locally-raised food.

The Extension System has continued to grow for the past 75 years and has proven to be one of the lead players in rural development. In most counties in the United States the "Extension office" and "Extension Agent" have become institutionalized, but are often taken for granted. The Cooperative Extension System still remains the single most important source of agricultural information for farmers and is also one of the primary sources of information in rural America on a wide variety of rural development and family issues.

The structure of Extension has remained relatively unchanged over the past 75 years, with support coming from local, state and federal sources. Its mission is to serve the needs of American agriculture and the nation's rural

people and communities. In some cases the strategies used have also proven successful in urban Extension projects which have become more prevalent in recent years.

Extension staff consists of a network of county-level Extension Agents who are part of county government and serve the needs of a specific county. They are selected from a pool of candidates approved by each state's Land Grant Institution, which also provides technical support services. Extension subject matter specialists are located at the state and national level and are responsible for providing training, technical resources, publications, and conducting applied research.

The primary program areas of Extension are divided into four areas:

1. Agricultural Production (the most important)
2. 4-H and Youth (the most visible)
3. Home Economics
4. Rural Development

Typically, every county in the United States has at least one Agricultural Agent, 4-H Agent and Home Economics Agent. These agents are primarily resource people and assist in coordination of many local events such as county fairs and 4-H clubs. Each year these agents are involved with conducting tens of thousands of local meetings across the country, distributing millions of pieces of educational material and providing one-on-one assistance to hundreds of thousands of individuals.

Since the beginning, the Extension Service has been concerned about the whole person. It has willingly addressed all types of human needs. During the early days, survival was questionable for many farm and rural families continually threatened by pests, drought, and the other unpredictable characteristics of agriculture and rural life. As farm production stabilized, programs expanded to include efforts to improve the standard of life in rural communities by improving the quality and nutrition of foods grown and processed by rural and farm families, and by improving rural leadership development. Topics such as pest control, sanitation, clean water, personal hygiene, child care and development, and literacy were on the agendas of many early Extension meetings. During the Great Depression and World War II, Extension was active in increasing food production and local self-reliance, and improving rural health. More recently, Extension has been deeply involved in such issues as youth at risk, child care, rural employment, rural education, health care, waste management and resource conservation. Even though individuals with disabilities were not an early target population for Extension, there is considerable evidence that they benefitted by Extension programs.

Clearly, Extension could have a much more substantial role in improving the quality of life of individuals with disabilities living in rural areas. The service delivery mechanism is in place, it is respected by rural residents, it has the potential for developing linkages with other service providers and, most importantly, it has the internal motivation to serve.

In the 1990 Farm Bill, Congress authorized funding to establish the USDA Extension Education and Training Assistance Program for Farmers with Disabilities. The program has two components:

1. Education and Training Demonstration Grants

   This program is designed to support cooperative agreements/programs between the Extension Service at the state level and private, nonprofit, disability organizations to provide on-the-farm education and technical assistance to individuals with disabilities and their families who live on farms or work at farm-related occupations. To date, eight demonstration sites have been selected in Indiana, Illinois, Iowa, Vermont, New York, Louisiana, Wisconsin and Montana (which serves Idaho and Wyoming). Grants will be used by the demonstration sites to initiate, expand or sustain programs that:

a. provide direct education and technical assistance.
b. provide educational programs for rural professionals and service providers.
c. provide on-the-farm assistance in identifying, selecting or fabricating assistive technology.

d. involve rural service providers in early identification of farm and rural families who could benefit from program services.
e. mobilize rural resources to address disability issues.

2. National Grant for Training, Technical Assistance, and Dissemination

This component is intended to support a national program of training, technical assistance, and information dissemination to support the state demonstration projects. The national program is to be conducted by a single Land Grant Institution in cooperation with the National Easter Seal Society.

In the Spring of 1991, USDA signed a cooperative agreement with Purdue University's Breaking New Ground Resource Center to fulfill the national program component.

With implementation of the USDA Extension Service Education and Training Assistance Program for Farmers with Disabilities, the Cooperative Extension System has taken a clear stand on its commitment to improve services to rural residents with disabilities and ensure their full participation in rural life. With the recent passage of ADA, the initiative is extremely timely and will draw upon the many newly-available resources.

For more information contact the Breaking New Ground Resource Center, Purdue University, 1146 Agricultural Engineering Building, West Lafayette, IN 47907-1146, (317) 494-1191.

Building Linkages, Collaboration, Networks

THE COMMON THREADS

♦ Start small and **make your successes visible.**

♦ Transportation is the most common rural problem; develop alternatives to public transportation and use transportation inventively. For example, assistive technology can be delivered to consumers by van

♦ **Informality is important in rural settings.** Rural people are interested in knowing who you are as an individual, not just as a professional. Recognize that individual agendas often don't coincide with those of agencies or professionals. Don't be in a hurry; **use your time flexibly.**

♦ Networking activities should be person-focused. Find out who does what well. Become familiar with local political, social, educational, cultural, and economic systems. **Develop state, regional, and local resource directories.**

♦ Encourage formal and informal interagency, **consumer-driven, collaboration. Build non-traditional coalitions and advocacy groups** of interagency councils, **consumer groups,** state advisory councils, business groups, community groups, schools, hospitals, home health care providers, extension offices, churches, fire departments, and sports teams. **Recognize the equality of services and respect persons and agencies.** Ensure reciprocity--group give and take develops cohesiveness and shared viewpoints. Collaboration may be the key to accessing some funding sources and avoiding duplication of effort. Share information, names, and problems. Invest time in looking for programs with compatible needs and resources. (For example, coordinate assessment activities with the local school system.) Look for groups that can help to meet each others' needs, such as senior volunteers caring for young children. Establish formal funding mechanisms to ensure that collaborative efforts result in follow-up activities. **Although much rural work is done at a personal level, formal working relationships are also necessary to clarify expectations and to satisfy outsiders** (such as funding agencies).

♦ Acknowledge collaborative relationships and reward the participants.

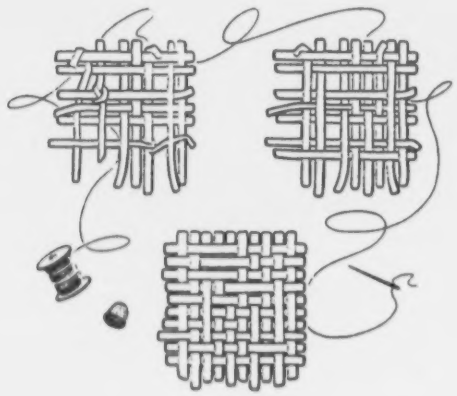
♦ Take advantage of available technology: Find and use toll-free numbers to access information. Use computers and telephones for networking and conferencing. Use public radio and television to broadcast information and to foster disability issue awareness in consumers, providers, and the public.

♦ Local contacts are necessary for establishing successful outreach programs. Explore the common interests you share with others in the community. View personal and professional friends and acquaintances as resources. **Work at public relations; use food as an enticement,** attend and participate in cultural and social events (dances, meetings, powwows, etc.). Join social organizations and attend their meetings regularly. Make

interagency meetings an opportunity for social interaction. Work with students and offer to be a resource for projects and presentations. Get consumers involved in public awareness fairs.

- Hire locally.
- Be "general practitioners"; there aren't enough "experts" in rural areas.
- Rural areas need information and referral services in multiple formats, especially in assistive technology.
- Each rural community is an individual; don't generalize among communities.

Small Group Facilitators: Mike Jakupcak, Tom Seekins, Julie Clay, Shawn Clouse, Phillip Wittekiend (Rural Institute on Disabilities), Michael Regnier (Summit Independent Living Center, Missoula), Charles Page (Community Medical Center, Missoula).



INTEGRATING TRAINING WITH SERVICES

FROM IVORY TOWER TO BARN RAISING:
A RURAL UNIVERSITY REHABILITATION PROGRAM IN PUBLIC SERVICE

Douglas A. Dunlap, Associate Professor/Program Coordinator (Presenter)

What is the desirable community role of a rehabilitation education degree program in a public university - particularly when the university is located in a rural community, in a predominantly rural state? Delivering significant rehabilitation-related services to the community, while simultaneously educating future rehabilitation service providers, has become central to the operation of the rehabilitation program at the University of Maine at Farmington. How this function developed - concepts, strategies, and methods - and the details of resulting rural community service activities undertaken by this university program, are presented in this paper.

The metaphor of a barn-raising is employed. Barn-raisings were community events in which residents departed from usual roles and responsibilities to contribute their talent and energy to a neighbor, to accomplish a task that no one person could do alone. Barn-raisings were essential to the economic, social, and cultural well-being of the community.

Program Nature and History

The Program in Rehabilitation Services at the University of Maine at Farmington was established in 1971 to meet human resource needs for developing state and federal vocational rehabilitation initiatives, and to provide appropriately prepared service providers in the context of deinstitutionaliza-tion of the state's two psychiatric hospitals. Over its 20-year history the program has developed the following community-oriented strategies: (1) a campus-based supportive employment program for people with disabilities; (2) a rehabilitation education outreach project bringing courses and training events, particularly in psychiatric rehabilitation, throughout Maine - literally from the Canadian border to the sea; (3) an advisory panel of community agency representatives to communicate service needs to the university; (4) an internship program through which approximately 30 students per year spend up to four months in rehabilitation-related agencies, mostly serving rural clientele.

A special dimension of the program is its undergraduate nature. While there are some 50 undergraduate rehabilitation programs in the United States, their relationship to rehabilitation as a profession, and to a sequence in rehabilitation education, is still in a formative stage. At UMF the program follows curriculum objectives outlined by the National Council on Rehabilitation Education (1987). The proactive nature of the program has aided recruitment of prospective service providers into higher education. As issues of disability develop a high profile across the state and nation, the program attracts both the life-experienced individual who decides to pursue a rehabilitation career, and the graduating high school student who has learned of such careers through school studies or community service. We are able to bring to our profession capable individuals who might otherwise have had limited accessibility to rehabilitation if graduate school was to be the rehabilitation education threshold.

In spite of its undergraduate status, the program offers training events to people beyond the bachelor degree level. Participants in outreach courses and institutes have included people with masters degrees, Ph.D.'s, and M.D.'s. This is done by providing continuing education units for professionals, linking with state agencies such as the Maine Bureau of Mental Health, to issue professionally recognized certificates. There are also linkages with graduate programs in the state to facilitate student movement towards graduate school.

The Maine Context

The Farmington campus is one of eight in the University of Maine system, and has 2,000 students studying liberal arts, education, and

human services. The town of Farmington has 7,500 people. Maine has 1.2 million people spread over 33,000 square miles. Canada borders Maine to the north and east, the Atlantic Ocean to the south. Ninety percent of the land is forested, and the pulped paper industry is the state's leading industry. It is a state of small towns, where a town-meeting form of local government prevails.

Challenges to rehabilitation service delivery that are familiar to most rural service providers are found in Maine: transportation, communication, isolation, and the cultural conflicts between the values of self-reliance and those of professional service utilization. Naturalistic dimensions add to the picture. This is a state with a long winter. Some people live on islands off the coast or on remote peninsulas. Others reside in remote logging communities, some from which it is easier, or even necessary, to leave the state, or even the country, to travel to services.

Strategies for Reaching the Community

Supportive Employment

A supportive employment program has operated at the university since 1987, serving more than 50 clients. As the largest employer in the town of Farmington, with nearly 350 employees, it was essential to any local and regional supportive employment initiatives that the university demonstrate the viability of this rehabilitation concept. As a community within a community the university has a wide variety of occupations - retail sales, food service, technical trades, printing, child care, clerical, media, for example. Further, the university environment is one in which, potentially, diversity as related to disability would be respected.

The university was approached by state officials in the fields of rehabilitation, mental health, and mental retardation - all of which incidentally are represented on the rehabilitation degree program advisory committee. Their inquiry followed a number of initiatives by faculty to meet local, regional, and state officials to inform them of our community service interests, and a number of productive student internships in all three areas. A model proposed was the highly successful Hospital Industries Program, a Maine urban project that utilized evening and night shift positions in a 24-hour facility (Balser et al, 1991).

The rehabilitation faculty embraced the idea of a campus supportive employment program, and formed a planning group that included the campus president as a member. The project was placed under administration in the organizational structure, with faculty acting in an advisory role. Modifications were made in the program design to fit a rural context. Most evening shift and night shift work was eliminated, as in a rural setting these may create isolation at work, and transportation difficulties. Supervision of clients was the responsibility of the departments in which they worked. A program coordinator and job coach assist supervisors.

Positions were made available in the print shop and a number of offices, along with food service and physical plant. Throughout the development and operational stages of the program, faculty functioned as advocates and resources. Presently the program is expanding into the rural region surrounding the university, with job development occurring in such operations as a ski area an hour's drive away.

Outreach Courses and Training

Since 1983 a summer institute in rehabilitation has operated with both service providers and program students as target population. Since 1985 there have been outreach courses and training events offered in geographic regions throughout the state, in response to community agency requests. In a rural state, instructor travel to various sites facilitates accessibility in the broadest sense. Out of the three major university terms annually - fall, spring, summer - two contain such courses. Locations have been literally from the Canadian border to the sea.

Most training events are offered as university courses for tuition. This method permits students as well as service providers to participate, enables faculty to include most training as in-load teaching activities, and enables payment at tuition rates - all favorable arrangements. For example, a recent outreach course in psychiatric rehabilitation drew 30 participants from a 60-mile radius, for 15 weeks, at a tuition cost of $192 per person.

A special emphasis of such courses has been psychiatric rehabilitation. One of the faculty has specific training in this area, and the university is the major training resource in the state for this aspect of rehabilitation. The outreach activity developed from a combination of faculty initative and state inquiry. It is a curiosity worth noting that initial state interest was in a university-based training, whereas the university advocated for the inclusion of significant off-campus service in the project. State mental health officials are now drafting requirements that people delivering psychiatric rehabilitation services must complete specified university training events.

Outreach activities serve the university well. They function as recruiting activities, and provide important exposure for program students. They also establish credibility and respect for the university as a public-serving, publicly-supported institution. Importantly, they keep the rehabilitation program in touch with local and state needs.

Advisory Committee

An advisory committee to the rehabilitation services degree program has been formed as another community-university linkage. Although there is no university or other mandate to establish such a group, faculty chose to do so. Membership includes representatives from rehabilitation, substance abuse, mental health, elderly services, corrections, mental retardation, and a governor's commission on supportive employment. There is a student member representing the campus rehabilitation student organization, and representatives from three other university system campuses, including a master's degree program in rehabilitation.

The group meets twice a year on the campus and advises on issues that may be appropriate for the university curriculum, or other university consideration. Equally important, the individual members are important resources who make guest presentations to courses, provide practicum and internship positions and create channels for initiatives such as the supportive employment and outreach training projects described earlier. Agencies represented by this group are an important core for an annual rehabilitation awareness day, a day of seminars, symposia, and displays about rehabilitation service.

Field Experience: Rural Practica and Internships

A 120-hour practicum and a 450-hour internship comprise the program field experience requirements. Students are encouraged to become involved with rural-serving projects statewide. Field experiences are structured to foster student development of positions, rather than placement in the usual sense. They must complete pre-field seminars that expose them to a variety of services, and prepare them to market their competencies. Approximately 60 students per year complete field work, and they have served in every county in Maine. Over half are offered jobs at internship sites - remarkable considering the undergraduate nature of the program.

The outreach orientation of field work has resulted in an extensive network of university contacts - further opportunity for collaborative ventures. It also provides important exposure statewide for rehabilitation education and rehabilitation services.

Networking Methods

Underlying the effectiveness of the initiatives described in delivering services to local communities, are a combination of external and internal networking methods. All strategies described result from faculty initiatives at making contact with service providers and administrators involved in rural service. These contacts lead to collaborative ventures, which in turn result in expanded networks. All faculty serve on one or more local, regional, or statewide boards or committees related to rehabilitation.

Program faculty are experienced service providers who have worked in rural areas as diverse as Appalachia, Pacific Islands, the American southwest, and rural Maine. While such experience may not be a requirement for these initiatives, it had caused all to recognize the community good will and potential that awaited initiative.

If networking external to the university was critical, so, too, was campus or internal networking. Administrative and peer support

is essential to community service, yet rehabilitation is a bit of an anomaly on an undergraduate campus. Our uniqueness has caused us to educate our campus about rehabilitation, which may be fortuitous. Faculty have been scrupulous about informing administration about public activity, and have involved students heavily in such activity. Current and previous presidents have met with state officials to explore and confirm collaborative relationships. The current president sits on the Governor's Supportive Employment Committee.

Annually the program conducts campus programs on disability. Faculty have sought out campus governance responsibilities, such as faculty senate and curriculum. The campus honors program has a rehabilitation course available to all majors. As the university faces responsibilities related to Section 504 of the Rehabilitation Act, and to the Americans Disabilities Act, the rehabilitation faculty is regarded as a significant resource, and has facilitated formation of a campus committee to advocate and plan for accessibility.

Community-Centric Values

At the core of whatever success this program has achieved is the assumption that the university, with its unique human resources, has a vital neighbor role to play for its rural constituent communities. A second assumption is that relationships are a foundation for action. It may apply in other types of communities as well, but surely it is frequently the case in rural communities that who you are must be established ahead of what you do.

The essential dimensions of neighborliness and personal relationship are surely an important core for successful initiatives to bring universities into rural public service.

Grateful acknowledgement is extended to colleagues Dr. Robert Pullo, Chairperson, Department of Human, Health, and Family Studies; Dr. Elisabeth I. Kalau, Associate Professor of Rehabilitation; Professor Roger L. Wing, Associate Professor of Recreation; Darlene Williams, Administrative Assistant

For more information contact the Rehabilitation Services Program, University of Maine at Farmington, Farmington, ME 04938-1911, (207) 778-7095 or (207) 778-2221 FAX.

References

Balser, R., Harvey, B., & Hornby, H. (1991). Supportive employment - a focus on job coaching, Rehabilitation Medicine Service, Maine Medical Center, 22 Bramhall St., Portland, ME 04101.

National Council on Rehabilitation Education (1987). Position statement on undergraduate rehabilitation education. Rehabilitation Education, 1(1), 19-27.

THE LIFE QUILTERS PROJECT

Donald K. Kincaid, Project Coordinator (Presenter)
Ann Krueger, Life Quilter
Charlotte Metz, Life Quilter
Susan Underwood, Life Quilter

The Life Quilters Project uses the Appalachian resourcefulness as exemplified by the traditional craft of quilting. In the hands of an experienced quilter, nonfunctional materials are assimilated and transformed into an inspirational, yet functional, work of art.

Similarly, The Life Quilters Project strengthens, develops, or combines community resources through the provision of a comprehensive and intensive consultation service to staff, parents, professionals, and individuals with challenging behavior throughout West Virginia. The Life

Quilters Project applies state of the art teaching, assessment, and management technologies to develop existing service providers' capacities to better meet individual needs. The project operates from a person-centered values base and a broad ecological perspective. The project supports individuals with mental retardation and challenging behaviors, who may be at risk of losing a community placement or may not be making progress towards greater independence, productivity and community integration.

Project Mission

The Project emphasizes the following outcomes as valued accomplishments in an individual's life:

- realizing greater participation in the community,
- developing more satisfying relationships,
- making choices in their daily lives,
- gaining respect and dignity through fulfilling valued roles, and
- achieving competencies in personal and social skills.

The ultimate goal of the project is to produce a more positive future for the focus individual and strengthen the overall service delivery system.

Project Benefits

The impact of the Life Quilters Project has been extensive, involving all levels of the service delivery system in West Virginia:

- At the program management level, the service organizations are assisted in developing resources, policies, and practices which maximize the effectiveness of their programs.
- At the program design level, organizations are assisted in planning, implementing, and evaluating programs for more effective living, working, and training environments.
- At the program delivery level, direct-service staff, supervisors, and specialists learn effective techniques, within a person-centered value base, for working with individuals with challenging behaviors.
- Finally, at the focus person level, the individual with challenging behaviors has an opportunity to more fully develop valued abilities and characteristics, to succeed in home, work, or school, participate in community life, establish relationships, make choices, and gain personal dignity and respect. Overall, the focus person can live a rich and positive life whether or not changes occur in the person's behavior.

Project Approach

The activities of the Life Quilters Project are conducted in a series of four phases, each with specific objectives. A significant amount of consultation time (100-500 hours) may be devoted to accomplishing the objectives of the four phases: **PLAN**, **LEARN**, **DO**, and **EVALUATE**.

Phase I: PLAN

During the PLAN phase, the Life Quilters staff are engaged in referral, screening, orientation, and agreement activities.

Referral - Referrals may be initiated by anyone within the community (i.e., case manager, parent, client, service provider, etc.). Criteria for referrals include the focus person being identified as exhibiting complex behavioral challenges, being at risk of losing or not receiving community placements, or not making progress towards independence, integration, or productivity. Currently, referrals are restricted to a class of individuals served as a result of a court decree, but plans are underway to make the Project available for all individuals with developmental disabilities in West Virginia.

Screening - During the screening process, project staff are assigned to review the information, identify all of the important individuals or stakeholders involved with the focus person, clarify the request and the services provided by Life Quilters, and review all information with other project staff. Project staff

jointly determine the appropriateness of a referral.

Orientation - Project staff provide orientation regarding the philosophy, goals, and function of the Life Quilters Project. Orientation activities may include providing written material, group inservices, or individual inservices.

Agreement - Prior to initiating the actual provision of services, staff meet with the key management stakeholders to obtain a profile of the stakeholder organizations, define the desired positive outcomes for the agencies, identify any problematic or facilitative systems issues, agree upon the goals of consultation, and identify contact persons and timelines for Phase II activities. These activities culminate in the development of a Memorandum of Agreement which identifies the roles and responsibilities of all parties involved in the Life Quilters process. This agreement is necessary to clearly define the activities, involvement, and support which will provide the foundation for the remaining project phases.

Phase II: LEARN

During the LEARN phase, staff are involved in a variety of activities aimed at bringing all of the stakeholders to a better understanding of the focus person and the goals of the project. Project activities include developing a personal profile, developing a Life Quilt personal futures plan, assessing the service delivery system, conducting a complete functional analysis, and identifying a work group.

Personal Profile - Project staff bring stakeholders together and use group graphics techniques to produce a personal profile of the focus person. The profile addresses the stakeholders relationship to the focus person, the person's history, health issues, people and places in the person's life, choices the individual is or is not able to make in his/her life, roles that are respected or disrespected, what works or does not work, and overall themes. This session provides an opportunity for an overall assessment of the individual and his environment.

Personal Futures Plan - The information from the Personal Profile is used to develop a personal futures plan or "Life Quilt". The stakeholders formulate a "best case" vision of the focus person in three to five years. The focus person's presence and participation in community life, opportunities to make choices, opportunities to gain respect and dignity, development of relationships with friends and family, and opportunities to exercise areas of personal competence are addressed. Environmental community and agency resources and barriers are examined. This activity affects the thinking, attitudes, and vision of the stakeholders as it relates to what is really important for the focus person and for identifying new directions to pursue.

Functional Analysis - Staff interview stakeholders, review data and records, observe the focus person in his environment, and videotape selected situations. This information is used to develop a functional analysis of the focus person's problem behaviors. The project staff may then make recommendations for environmental changes or develop needed intervention plans.

Service Delivery Assessment - This activity is an indepth analysis of the focus person's daily activities and the services provided for him/her. Through task analysis, daily routines of life are assessed by examining each component of the day, determining the focus person's strengths and needs with regard to the tasks, determining the goals and teaching strategies currently used, analyzing staff training needs, and, finally, addressing systems issues that affect the delivery of services.

Work group - Based upon the work now accomplished, a group of individuals must be identified to begin to address issues and solve problems. This work group is established with clearly defined roles and responsibilities and with clearly identified guidelines for conducting effective and efficient meetings. With the formation of a work group, Phase II is complete.

Phase III: DO

During the DO Phase, the work group identifies goals, develops a work plan,presents the work plan to stakeholders and management for approval, and initiates the actions in the work plan.

Work plan - The work plan indicates desired outcomes, needed actions, responsible persons, and designated settings and timelines for the actions to occur. The work plan is presented with

a summary of Phase II work to the management(s) for their approval. All stakeholders and critical management staff sign the work plan to indicate their support of the goals and methods of the project. The work plan is also presented to the focus person's interdisciplinary team for approval and may be incorporated into the person's individual program plan. Monthly reports on the progress of the work group are completed by the Life Quilters and distributed to management and stakeholders.

On-site Teaching - During Phase III one of the major project activities is the training of individuals providing services to the focus person. Individuals may be trained in general behavior management procedures, guidelines for interacting with the focus person, specific behavior programs, or teaching the daily life routines. For the most part, training is conducted in the natural environment and makes use of community-based, positive behavioral support techniques and video technology.

Phase IV: EVALUATE

The final phase has three goals; to evaluate the project's progress, to determine whether to "close" the project, and to produce a final report.

Evaluation - The progress of the project is reviewed every 30 days from the establishment of the work group. The Life Quilter staff conduct a "peer review" of project progress each month and team problem-solve solutions to specific situations and problems. Approximately every 90 days all of the stakeholders assemble for an update on the specific project activities and successes. Life Quilters staff continue to document all project outcomes and accomplishments, and conduct interviews and surveys to determine project success as most or all of the identified objectives are completed. The formal project evaluation assesses 31 areas related to the focus person's quality of life and personal development, staff and organizational changes, and the team's effectiveness. This evaluation also measures the participants' perceptions of the number of identified objectives met and whether the project should be closed.

Project Closure - If the management and stakeholders feel that the project objectives have been reached, then a decision is made regarding project closure. Project staff continue to provide assistance and consultation to the project as it is implemented by the stakeholders. If further in-depth consultation is required, another work plan is written and signed.

Final Report - A final report is prepared detailing the background, methods, and accomplishments of the project, along with a plan for the future. This report is produced in a narrative format by Life Quilters staff with the cooperation and participation of the focus person and the stakeholders. This narrative story is then distributed to interested individuals throughout the system. This narrative serves to reinforce the successful efforts of cooperating agencies and also allows for the communication of effective techniques and ideas throughout the system.

Current Status

The Life Quilters Project is completing its second year of support. Currently, there are 19 active projects involving 29 different state agencies and organizations.

What We've Learned

What doesn't work:

- "Traditional" short-term consultation from the "smart guys".
- Narrow consultation that does not address all of the variables affecting the individual's life.
- Being viewed as "another pair of hands" instead of as a resource to assist the agency to develop their own capacities.

What does work:

- Including all of the stakeholders in planning, decision-making, carrying out tasks, and evaluating the outcomes of their efforts.
- Allowing everyone to freely and openly communicate their opinions and points of view between and within agencies.
- Expanding the range of possibilities and encouraging creativity.

- Focusing on the person and encouraging his/her participation/leadership.
- Culturing commitment from all levels of an agency/organization.
- Providing service agencies with an "impartial" view of their services and programs, which improves the quality of services and makes for more effective advocacy.
- Cultivating local talent within the work group and within the community.
- Focusing on the work plan (long-term, proactive) instead of on frequent crises (short-term, reactive).
- Empowering the local work group to make substantial changes in the support provided and in the system itself.

For more information contact the University Affiliated Center for Developmental Disabilities, West Virginia University, 918 Chestnut Ridge Road, Suite 2, Morgantown, WV 26506, (304) 293-4692, (304) 293-7294 FAX.

THE FAMILY CAREGIVER PROJECT

James R. Cook, Ph.D., Associate Professor of Psychology
C.D. Fernald, Ph.D., Associate Professor of Psychology (Presenter)
Catherine A. Gutmann, Dr.P.H., R.N., Assistant Professor of Nursing

Education and Support for Families of Rural People with Disabilities

Many individuals with severe, chronic disabilities require comprehensive care from others. For example, severe mental illness, developmental disabilities, and the dementias and physical limitations of aging may require lifelong support and periodic acute care. In the past, many of these needs were provided through institutional placement, but families have taken on greater responsibility in recent years.

Family caring for a severely disabled person can be difficult, and current trends have increased the demands on families. For example, the population is aging and the number of families caring for impaired elderly relatives has increased. Because of improvements in technology, individuals with fragile medical conditions are surviving longer, but with increased needs for long term care from families and others. Deinstitutionalization and shortened hospital stays require families to play a larger role in treatment and long term care. While women have traditionally been the caregivers, they are now more likely to assume career responsibilities and return to the work force. Many families are faced with caring for both growing children and aging parents.

Service Trends and Rural America

While these trends have affected the entire country, rural America is particularly sensitive to these changes. Rural areas frequently have fewer services for families coping with disabilities. This lack of services means that rural families are likely to experience more intensely the difficulties of caring for an impaired family member.

On the other hand, rural communities often have a tradition of individuals knowing and caring about each other. Individuals in small, close knit communities come to depend on each other for help with the difficulties they face. In the absence of a large collection of human service agencies, rural people often depend on churches, neighbors and family doctors, rather than specialized agencies or professionals.

Many interventions have been developed to help family caregivers get the information and support they need. Yet many of these programs assume there are sufficient numbers of professionals to conduct the programs. They generally target groups of caregivers who face a particular disability. Unfortunately, in rural areas there may not be adequate numbers of people with the same disability in the same community for these interventions to be useful.

The "Caring Families" Approach

The Family Caregiver Project at University of North Carolina at Charlotte has developed an approach to helping family caregivers which is particularly suited to the needs of small rural communities. Central to this approach is a series of Manuals that provide practical information to family members. The "Caring Families" Manuals also help caregivers obtain emotional support from other family members, friends, other caregivers, and professionals.

There are several reasons why the "Caring Families" approach is particularly suited to the needs of families caring for disabled relatives in rural communities. First, it can be used easily with different types of disabilities. Most intervention programs for family caregivers target one particular type of disability. Creation of a group for education or support then requires sufficient numbers of people with the same disability. The Caring Families Manuals emphasize the common elements in caregiving, regardless of the type of disability. While the Manuals provide information specific to particular types of disabilities, the emphasis on common themes (and parallel structure of the Manuals) can help families learn from and support one another. This makes the Manuals suited to small communities which may lack the numbers to have more specialized groups. Thus, family members from the same church, business, or neighborhood who know each other already, can come together to use the Caring Families Manuals as they find out more information and provide support for each other.

The second way this approach is well suited for rural needs is that it does not rely on professionals to lead goups of caregivers. Since trained professionals are often in short supply in rural communities, the Caring Families Manuals include a "Leader's Manual" which provides detailed instruction and experiential activities to help untrained individuals lead groups of family members. Other caregiving families can often provide the best help by virtue of their experience.

The third way in which the Caring Families approach is suited for rural communities is that it is family-centered. Traditional family values are emphasized in the Caring Families Materials. Families are viewed as the experts on family caregiving. They know their loved one better than anyone else. They can benefit from the information and experience of professionals and other caregivers, but they must feel in charge of the care of their family member. The materials also emphasize the value of involving the whole family, not just one member. The extended family groups which exist in many rural communities can benefit from this approach.

The Caring Families Manuals

A series of four Manuals has been developed. Three of the Manuals address the needs of people who care for family members with specific problems: mental illness, developmental disabilities, and aging. In each of these Manuals, several chapters discuss issues which are common to all caregivers, regardless of the condition or disability which affects the family member. Other chapters contain information specific to the particular problems which the relative faces. The Manuals were designed to be "user friendly" and include many practical tips on coping with day to day problems. The materials are fully coordinated so that families can use and study the Manuals easily with other families, regardless of whether the impaired relatives have the same or different conditions. The Leader's Manual can assist groups who are meeting for education and support.

The Manuals can be used as guides and reference books. Families can get an overview of information about caregiving, about their relative's impairment, and about how to cope. They will not find all the answers but should discover ways to find additional information. Other resources are listed at the end of each chapter. A loose-leaf format makes adding new

information, magazine articles, pamphlets, notes from conferences or meetings easy. Caregivers often find it helpful to get together with other caregivers to compare notes and share tips. A group of caregivers can go through the Manuals, one chapter at a time, discussing and sharing.

Throughout the Manuals, the notion of empowerment is emphasized. To succeed, caregivers need to feel they are in charge. Empowerment implies a basic respect for the integrity of the caregiver. Caregivers with a sense of empowerment are better able to meet professionals on an equal basis, with both bringing specific information and skill together to provide the best care possible. Empowered family members rarely tolerate the demeaning or patronizing attitudes too often held by professionals. The Caring Families Manuals acknowledge the diversity among caregivers. Sections can be scanned easily so that readers can decided whether to study material in depth or skip over familiar or irrelevant material. Resources are listed so that interested readers can easily find more detailed information. The Leader's Manual offers a full array of choices so that the group can be tailored to members' needs.

The materials can be copied and shared. The Manuals were developed through the support of the Office of Human Development Services of the U. S. Department of Health and Human Services. All of the materials are part of the public domain, and organizations are encouraged to copy and share them.

Topics

The major topics covered in each of the Manuals are:

Succeeding at Caregiving
- Helping Families Succeed
- Finding Sources of Help
- Reducing Stress
- Coping with Common Difficulties

Basic Information about the Disability
- Types of Problems
- Kinds of Services

Coping with Day to Day Problems
- Creating a Safe and Supportive Home
- Managing Behaviors
- Dealing with Specific Problems

Financial and Legal Concerns

Planning for the Future

The Development of the Materials

The materials were developed by a multidisciplinary team from the University of North Carolina at Charlotte, including faculty members from psychology, nursing, special education, human services, and social work. They reviewed the professional literature to build on existing work.

The team also relied heavily on the experiences of family caregivers and professionals who regularly work with families. Team members attended consumer conferences and listened to family members. Family advisory groups provided "expert" advice to the professional team about content and writing style.

Conclusion

The Caring Families Manuals are a unique resource for rural families who are coping with disabilities. The Manuals can help provide education and support for groups of otherwise isolated people who face different types of disabilities. Helpful information about everyday coping, emotional support, and starting education/support groups can reduce barriers to rural families facing disabilities.

For more information contact The Family Caregiver Project, Department of Psychology, The University of North Carolina at Charlotte, Charlotte, NC 28223, (704) 547-4758.

References

Biegel, D.E., Sales, E. & Schulz, R. (1991). Family caregiving in chronic illness. Newbury Park, CA: Sage Publications.

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DISABILITY RIGHTS AND ADVOCACY

Bill Malleris, Agency Director
Robin DePagter, Outreach Director (Presenter)

The Southeastern Minnesota Center for Independent Living (SEMCIL) has developed consumer-drivenAccess/AdvocacyCommissions in Rochester, Winona, and Red Wing, Minnesota.

Rochester is the main office of SEMCIL; Red Wing and Winona are fully staffed branch offices developed to serve the rural areas of Southeastern Minnesota. Each branch office has two professional staff and two or more peer visitors to serve three counties in their respective areas. Located in farming communities, these offices receive support and guidance from Rochester, but remain autonomous to meet the varied needs of persons with disabilities who choose to reside in rural counties.

To ensure consumer representation and input, each outreach office has a Consumer Advisory Council and an Access/Advocacy Commission to provide policy direction for programming. The membership on each Access/Advocacy Commission consists of persons with disabilities or their family members. This not only reflects SEMCIL's philosophy of consumer control, but also ensures that the issues addressed are those that are important to each community.

The purposes of the Access/Advocacy Commissions are threefold:

A. To provide an arena for persons with disabilities to learn the necessary skills to advocate for themselves, and on a local, state and national level.
B. To provide the opportunity for consumers to take an active role in their community and advocate for positive change.
C. To address accessibility and advocacy issues relevant to each rural area.

This creative approach provides local control, consumer focus/development and complete consumer involvement. The consumers have the responsibility to identify, plan, and implement the goals identified by the Commission.

The first SEMCIL Access/Advocacy Commission began in Rochester in 1989 and the Commission was initiated in Red Wing in the fall of 1989. In the spring of 1990, the Access/Advocacy Commission was formed in Winona. Each outreach office used a format established and tested in Rochester as its blueprint. One major component of the format was modified to meet the needs of the rural area: individuals from the smaller communities surrounding the branch offices were included in the membership. This ensured that the concerns of individuals residing in all rural counties were represented.

The accomplishments of the Access/Advocacy Commission have been exciting and varied in each of the communities. The Red Wing Commission initiated an access awareness program in the fall of 1989, proposing that the city install 40 curb cuts. To date 20 have been installed and 20 will be installed in 1991.

Simultaneously, work began on extending the City of Red Wing's current Dial-a-Ride paratransit system. With assistance from SEMCIL's Access/Advocacy Commission, the City of Red Wing received 60 percent of the funding to expand the existing service from the Minnesota Department of Transportation. The Access/Advocacy Commission assisted the city in raising the other 40 percent. Hours of service have been substantially increased.

The Commission and Red Wing Community Education co-sponsored a training session for consumers and human services professionals on use of the Dial-a-Ride system. A disability awareness training session for bus drivers was also implemented.

Unexpected close partnerships with Red Wing city officials have occurred since the inception of the SEMCIL Access/Advocacy Commission. City officials have asked commission members to be involved in regular City Council meetings, the City Safety Council, and the Chamber of Commerce. Red Wing's

BEST COPY AVAILABLE

Human Rights Commission has asked the Access/Advocacy Commission to develop a guide to accessible businesses, restaurants, theaters, etc. Other partnerships have developed with Community Education and with Red Wing Advocating Change Together, a developmentally disabled advocacy group.

The Commission in Winona has had similar success. It also began work simultaneously on two initiatives: obtaining 33 new curb cuts in the city, conducting consumer bus training and teaching disability awareness to bus drivers.

Commission members developed good working relations with the City of Winona planner and the city engineer. This allowed the Access/Advocacy Commission to propose new curb cuts in strategic locations in Winona.

Meetings with the City Clerk and Winona transit officials led to a joint decision to hold consumer bus training for consumers with disabilities, and disability awareness training for bus drivers. The SEMCIL Access/Advocacy Commission and the city of Winona co-sponsored a bus training session in July, 1990. Seventeen consumers and 10 interested professionals attended the session. To minimize apprehension, consumers practiced using the bus wheelchair lifts. The drivers became aware of various disabilities and the different types of wheelchairs. Changes proposed and implemented included: larger route signs on buses, seats removed to increase space for larger wheelchairs, and seat belts for those individuals who prefer to transfer into a permanent bus seat.

There were many constructive results: a positive working relationship with the City of Winona, increased ridership (prior to the training session the monthly average lift use was zero to three rides per month; since the training, the average is approximately eighty rides per month); major changes were made to all buses to accommodate persons with disabilities.

The Access/Advocacy Commission has encountered one major obstacle. There are few trained personnel to provide technical assistance to facilities on improved accessibility. Each branch office is only staffed by two full time individuals who are responsible for coordinating and providing the full realm of SEMCIL services.

To develop this program to its full potential, Access Technicians will be trained to enhance and assist with implementation of Commission recommendations. Two Access Technicians recruited from the Commissions will be brought on as contract staff in 1991.

These individuals will have developed the necessary skills as Commission members to effectively advocate for accessibility changes in their communities. They will also receive additional training on ADA and federal code requirements so they can assist in developing modification plans. Using a proactive approach, the Access Technicians will provide the following services to businesses and organizations:

1. An on-site evaluation will be conducted with the organization's permission.

2. Trained personnel will determine necessary modifications and an accessibility plan will be submitted to the organization for review and input.

3. For organizations choosing to complete modifications, the following resources will be available:

- Persons knowledgeable of codes and regulations at the federal, state, and local levels.
- A solid working relationship with the Building Safety Department.
- A list of distributors and cost figures.
- Assistance in planning the most cost effective way to make changes.
- Training for architects and contractors.
- Availability of experts in the field.

4. On-site training for personnel on disability awareness & sensitivity will be provided.

In late 1991, the Access/Advocacy Commission will be implemented in our third branch office in Owatonna.

All SEMCIL programs are available, at no charge, to any person who has a permanent disability.

Approximately 20% of the disabled population have been served through SEMCIL's Outreach

Offices. The rural outreach initiative is still in the infant stages for SEMCIL. In the next four years, an extensive outreach effort will be made which will result in permanent offices and staff in all eleven counties that SEMCIL serves. Access/Advocacy commissions will be implemented in each county and technicians hired during the phase-in process. We anticipate that we will reach many additional consumers through this effort.

Access/Advocacy directly affects approximately 75-100 consumers in each area. However, the indirect effects and the numbers of individuals who have, or will, benefit from these services far outnumber those we are able to track.

For more information contact Southeastern Minnesota CIL, Inc., 1306 7th Street NW, Rochester, MN 55901, (507) 285-1815.

Integrating Training with Services

THE COMMON THREADS

♦ Not only designated "trainers" provide training in rural areas; most people involved with disabilities train consumers, family members, staff, related professionals, or community members at some time.

♦ For effective training, people need to see themselves as experts participating in a common effort; use participatory formats. Establish credibility. Get consumer input on training needs and delivery methods; personalize training. Use consumers' talents; the best trainers have first-hand knowledge. Personal experience produces expertise and gives training validity. Get local community members to provide training. Identify local and regional training resources.

♦ Know your territory, local concerns, and local customs. Be sensitive to local and cultural issues. Don't generalize training across communities simply because they share a geographic area; adapt curriculum and methods to individual needs.

♦ Training is on ongoing process, with new areas and strategies evolving constantly. Assess training needs, and **provide for ongoing training evaluation** and participant pre- and post-training input. Relate the known to the unknown, the familiar to the unfamiliar. **Be flexible**; don't have a rigid agenda for time, sequence of instruction, or curriculum. Use a variety of methods: **support groups**, peer counseling, round table discussions, public tv, in-home training, disability-related periodicals, transition guides. Explore unusual content, such as adapted aquatics or driver's education. Provide transition training for consumers and their families at every transition point in a consumer's life. **Expand the rural program's ability to provide activities recommended by occupational, physical, and speech therapists.**

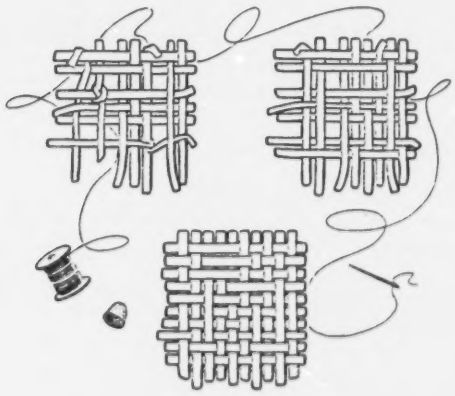
♦ Keep it simple. Train in the consumer's language; what are the consumer's operational definitions? Train consumers in their homes or deliver training from vans. Anticipate that personality conflicts are always a possibility; trainers and consumers aren't always going to like each other. Allow people to share their experiences; don't just talk at them.

♦ Coordinate inservice training with other agencies in the community. Trade local expertise instead of spending money to bring in outside "experts". **Rural agencies can provide outreach in-service training to agencies in other rural communities or can share training resources. Use local hospital resources, such as OT's and PT's as trainers.** Share in-service training with local nursing homes. Use junior college, vo-tech, college and university faculty as staff trainers (while educating <u>them</u> on disability issues and training needs). Use consumers and local vendors as staff trainers. Allocate funds specifically for staff training; this will make training a priority. Integrate staff training into informal situations, such as staff meetings. **Emphasize staff's existing competency; training is an opportunity to acquire <u>additional</u> skills. De-emphasize weaknesses.**

♦ Establish open communication among providers, consumers, families, community members, etc. Educate consumers on the rights and responsibilities of community membership. **Train the public in disability awareness,** including psychiatric disability. Look for consumers in the business community who can help **build a consumer/provider/business coalition.** Invite local business people to public disability awareness meetings; educate them on the Americans with Disabilities Act. Alert the local media to disability-related events (e.g. national and state observance weeks). Disseminate information to local schools.

♦ Train special audiences, such as personal care attendants, lawyers, doctors, etc. Psychiatric therapists can provide training on psychiatric disabilities for other disability professionals.

Small Group Facilitators: Mike Jakupcak, Kathleen Miller Green, Sue Forest, Phillip Wittekiend (Rural Institute on Disabilities), Barbara Larsen (Summit Independent Living Center), Charles Page (Community Medical Center, Missoula).



SUPPORT SYSTEMS

DEVELOPING A RESPITE PROGRAM IN A RURAL COMMUNITY

Maribeth Culpepper, L.M.S.W. (Presenter)
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Respite care is a relatively new concept. It has grown out of the national movement of the 1970s to de-institutionalize and provide treatment settings for persons who are disabled which are least restrictive and which most closely resemble standard community living. The purpose of respite care is to provide an opportunity for families of individuals who are developmentally disabled to get away for an evening, a weekend or several days; time to "recharge" or to provide backup to families in emergency situations, such as the illness or hospitalization of a family member.

There are several models for providing respite care. Most are agency-based (where an agency takes the lead in recruiting and training providers and linking families with providers) and many are urban and center based. In the urban models, providers are trained in groups and this is possible because of the larger population from which to recruit providers. In center-based models, a building or part of a building is available and staffed some or all the time so that families who need respite have easier access to the service.

In large, sparsely populated rural areas, center-based urban models for provision of respite and recruitment and training of providers is often not possible or appropriate. Many families as well as potential providers live in more isolated settings, some without electricity, telephones, indoor plumbing or heat other than wood. People do not concentrate in large numbers in one location, as they do in cities, and villages or isolated homes are often many miles apart. Transportation is often a problem. These factors make a centralized location for respite less practical and accessible. They also contribute to difficulty recruiting and training providers; newspapers, radio stations, personal and telephone contract are harder over such a scattered population; the number of providers who reed training at any one time often is too small for group training; and centralized location for trainings are hard to schedule for the mutual convenience of all providers. Training needs and formats may differ, too, since providers may be family members or close friends of the family for whom they will be providing respite, thus needing less individualized training concerning each client. Many providers do not read or write and many may be Spanish speaking, with limited understanding of English even when material is presented verbally.

Yet rural families need respite from the care of their family member who is disabled at least as much as urban families do, and provider training is a critical element in the peace of mind of families when they leave their family member who is developmentally disabled in the care of another person.

Family members must feel reassured that their family member is safe and confident that the caregiver is competent to deal with their family member's particular needs.

Families also need dependable relief from the intensity of attending to the needs of their family member who is developmentally disabled. Respite care which involves paid providers, when it is available, is often limited because of funding considerations. Volunteer respite providers tend to either quickly tire and become unreliable or prove less than qualified to address care systems, to break down as caregivers, admit their problems, and demonstrate their need in order to obtain respite.

The philosophy of respite, on the other hand, is to strengthen families who keep their family members who are developmentally disabled at home through prevention of stress and crisis, when possible, and through consistent, dependable support. The purpose is to support families before there is unnecessary stress or breakdown. Families with this kind of support are more likely to remain a functional unit. A second major function of respite is to have

providers available in a crisis situation when emergency respite is necessary to reduce further stress for a family.

During 1987-88, Las Cumbres Learning Services developed a model for the provision of respite services in a large rural areas of North Central New Mexico. This model was developed through our experience with a tri-cultural population (Hispanic, Anglo and Native American) in a large rural region. Families served ranged from those who live in very isolated situations with few economic resources to upper-middle class families living in more populated communities. Input from a statewide Respite Network is also reflected in the model. Many aspects of the model may also be pertinent to respite services in non-rural areas, as well, and/or can be adapted to suit the needs of the geographic region where respite service will be started.

Any interested individual, network of individuals, or agency can begin a Respite Program in any community. Most often existing agencies serving individuals who have developmental disabilities add respite to the range of other services they provide. However, another agency or a network of parents could also begin a respite program in a local community. Clear commitments from individuals involved in the initial effort should be obtained as to who will do which step of the process. Written working agreements are helpful if several individuals and/or agencies are working together in the effort.

How to Start

Needs Assessment

The first step for anyone interested in starting respite services is to determine if there is a need in the local community for services. Starting a respite program is no easy task, and you want to be sure there is a need for such a program. Also, funding sources will want to see that a need exists before considering funding a new program in any community. Start by:

- defining the geographical region you want to serve (will it be limited to one town, county, or region?)
- defining the population you will serve (i.e., will you serve only individuals who are developmentally disabled or will you provide respite services to other types of disabilities?; families of people with mental health problems?; families of elderly stroke victims?; etc.) While the Las Cumbres model is for families with developmentally disabled members, many aspects of it could easily be adapted to other populations.

Then conduct a needs assessment for the population and within the geographic region you have defined.

A needs assessment can be conducted in one or a combination of several ways:

- a form which is widely disseminated throughout the community and collected and collated by a central person or agency. Forms can be distributed to local Associations for Retarded Citizens, special education classrooms in public schools, community based agencies serving the developmentally disabled, local churches, public health clinics, hospitals and doctor's offices, local human service agencies (such as Social Services), and/or state agencies such as Health and Environment Department or Human Services Department. Some information can be gained through the CO-OP System, Developmental Disabilities Division, Health and Environment Department, concerning who in your region is on a waiting list for respite services. If at all possible, determine who in each setting will be responsible for disseminating and collecting the form and getting it back to a specified central collating location.

Set a date for return of the form and put that date on the form. It is most effective if the form is combined with personal or phone contact for follow-up, since mail returns of forms received, even with self-addressed stamped envelopes tends to be slow. Follow-up phone calls, meetings, or personal contact will glean a wider response.

- media, articles in newspapers, spots on the radio, flyers grocery stores, schools, daycare centers

- a widely publicized meeting of interested individuals

- informal data collection from interested individuals

In all needs assessment formats, find out how many people are interested, if they have ever or are now receiving respite through some auspices; how much they project they would use respite and time periods when respite is most needed (i.e., after school, weekends, evenings, for a week at a time, etc.); and about their willingness or ability to help pay for services. You will need the name, address and phone number of the respondent so you can reach him/her and you need to know the name, age, and type of handicap (including whether or not they are ambulatory). Information about the type of care the disabled family member will need is very helpful in planning the program and recruiting and training providers and matching them with families.

It is also helpful to find out if the family knows of anyone who would provide respite or be interested in being trained as a provider, since, especially in rural regions, recruiting providers can be one of the biggest problems. Las Cumbres'needs assessment also asked what kinds of training families felt providers should have in order for families to feel comfortable leaving their disabled family member with them. This information helps with the design of provider training formats, which impacts total respite program costs.

Decide How and Where Respite Will Be Provided

There are several options for how to provide respite. You can choose one or a combination of the following choices. The ideal is to create a continuum in order to offer families as many options as possible, but often a small, sparsely populated area must choose one.

"Center-based" respite is just what it sounds like: respite care provided in a "center" or a central location. This might be accomplished in several ways.

Respite Center

Some agencies in larger towns have a building designated solely for the provision of respite care which is staffed 24 hours a day, seven days a week (or other regular, specified hours) so that respite is always available (providing there is an empty bed) to families who need it. The number of beds in a center--based respite program may vary according to the needs and the funding available.

Designated Respite Bed(s) in an Already Existing Location Unless a respite program exists in a fairly good-sized town with enough people needing respite and an adequate funding base, a center set aside solely for respite is sometimes impractical. Other center-based options can include a bed (or more) set aside in an already existing location.

One possibility is designating extra space in an existing group home as a respite bed. The advantage of this arrangement is that there is already staff at the group home who may be able to function as providers, thus averting the need to find a provider in a hurry. Other advantages are the already structured programs available in group homes and day programs, from which respite clients may benefit.

There are disadvantages to this. The respite person(s) must not make the total number of people exceed the number for which the group home is licensed. Client room requirements must be met for licensing. Another drawback is that children cannot be served in group homes for adults, so a bed in a group home would be limited to use by respite clients age 16 and up.

Home-based

Home-based respite services are sometimes called "provider based" models and are often most practical in non-urban areas where center-based services do not exist; or home-based can be combined with small center-based programs to create a wider range of options for the provision of respite. Home-based services are considered most "normalized" for the provision of respite to children. Home-based services can be provided in:

- the provider's home
- the family's home
- a combination/choice of the above

Providers can be hired as staff persons or work on a contractual basis (but usually not both, because the Department of Labor does not allow employees of agencies to also work for the agency on contract). If you are considering hiring a current employee to also do respite, check DOL regulations concerning paying individuals who work more than 40 hours a week.

Other Ideas

- Volunteer vs. paid providers. Some programs operate strictly with volunteers; others pay their providers.

- Provider on call. Some agencies hire or contract with a staff person or contracted person to be available ("on-call") in the event of an emergency respite need.

- Before/after school. Limited respite needs could be met by exploring utilization of a day care center or school facilities for before/after school respite care. Such an arrangement could be utilized on a planned basis, or if resources are available to have appropriate staff available, even on a "drop-in" basis.

- Transportation as respite. Many families, when they identify what would provide a break for them, say that the transportation of their disabled family member to programs, appointments, etc., could provide them with a lot of relief. Consider this as one option for the provision of respite. Look into legal/liability issues and providers' driving records first. Families should request and agree to this form of respite and should sign a release concerning their family member being transported by a provider. Providers who drive clients should have their own liability insurance; agencies sponsoring programs where this is an option need proof of that insurance as well as a copy of the provider's drivers license and driving record.

- Respite for individuals who are disabled. Adult and adolescent disabled individuals may need a break from their families (or the group homes in which they live) from time to time. Respite services might be used to organize social outings, find another place for the person to stay for awhile, or otherwise meet the needs of these disabled persons.

Allocate Respite Hours

While you are considering the budget, you will doubtless have in mind a total number of respite hours which you hope to and can afford to provide. Allocation of these respite hours among families needing and requesting respite can be a problem, primarily because there are never enough hours to meet all requests. To allocate hours fairly, Las Cumbres has devised a system to determine a family's need based on things such as; family structure; geographic isolation and behavioral concerns, independent living skills, and mobility of the family member with a disability.

Waiting List

When you are unable to provide requested respite services because of funding constraints, applicants must be put on a waiting list. Keeping accurate records on wait listed families and their unmet needs is an important function: you also have data which will support requests for more money to provide respite to those receiving no or limited services.

In addition to keeping internal records and entering data into statewide systems, agencies should refer waiting families to other respite resources as well as to other needed services. Las Cumbres touches base with respite waiting list families quarterly in order to update their needs and let them know the status of their position for potentially receiving respite. Emergency respite could also be offered to waiting list families in emergency situations.

Emergency Use

Emergency respite is a problem for several reasons in a rural setting. one dilemma is most geographic regions is defining "what is an emergency?". A good bit of discretion is required from the Respite Supervisor in

exercising judgement about this matter. However, we have defined some guidelines. The following factors may be considered in assessing the nature of each family's emergency request:

A. Is the client being abused or neglected?

B. Is the client at risk of abuse or neglect?

C. Does the client exhibit behavior problems that pose a threat of injuring self or others or that result in destruction of property?

D. Has an act of God occurred (fire, flood, tornado, etc.) which has resulted in disuse of primary residence of the client?

E. Is there recent hospitalization or serious illness of primary caretaker, immediate family members, family member who is disabled?

F. Is the client in danger of institutionalization or a move to a more restrictive environment?

G. Is there other extraordinary family stress (e.g., potential illness, hospitalization or other absence of primary caretaker if respite is not provided)?

Other problems are insufficient respite hours and unavailability of providers for emergency situations. Total number of respite hours available for a year are always limited and are not usually sufficient to reserve for an emergency respite fund, so unless families can afford a private pay situation, funding for emergencies is a problem. Furthermore, without a center-based model which is available all the time, a respite provider may not be available for family emergencies.

Las Cumbres has sought to deal with these problems by (a) making a bed available in a group home for emergency use when a provider can't be found or when this is the most appropriate setting for a respite client (however, remember, this is not a resource for clients under age of 16; (b) encouraging families who are or the respite program to plan respite use so that some of their allocated hours are available for emergencies, should they occur; (c) reserving a small number of HED funded respite hours for emergency respite use; and (d) encouraging providers to accept emergency respite cases.

At Las Cumbres, the emergency respite fund is available only to families who are not already on the respite program. This decision was made because there is already a growing waiting list for respite services, and families who are not already receiving some allocated respite hours in a year are likely to be most in need in the event of a true emergency. Other families' unused hours may be added to the emergency fund as the year progresses if needed. The Respite Supervisor monitors emergency hours use and the need for and availability of additional hours. If no emergency hours are available in our program and a family is truly in need, Las Cumbres looks for other resources by contacting other respite agencies in the State.

Publicize the Program

Once you have identified families who want respite, have decided what model(s) to use and know about what it will cost and where to get the money, it is time to publicize the program. If your resources are as limited as most new respite programs are, you may already have identified all the families you can serve and may want only a short newspaper article announcing the service.

However, the purpose of publicity is threefold in letting the community know the program exists to:

A. Families who need the service know it's there and how to link with it;

B. People who might be interested in being providers can be recruited; and

C. Potential funding sources (donations, etc.) can be solicited.

As you publicize the program, other groups than the one you are currently targeting who have a need for respite may also be identified and considered for service in the future. For instance, if your target population is families of developmentally disabled originally, but families

with members with other disabilities surface as a result of publicity, you may want to consider expanding your mission to serve a broader population in respite services.

Publicity can be done through:

- press releases
- radio/TV/other media announcements
- speeches to interested groups
- personal contact with families, potential providers
- flyers to be distributed in grocery stores, churches, and other places where families go
- notifying family doctors, pediatricians, and other health care professionals and through other means as well.

Recruit and Approve Providers

Providers of respite services at Las Cumbres must be at least 18 years of age, due to liability issues and the requirements of some funding sources in New Mexico. Recruitment of providers goes hand in hand with publicity, and as mentioned provider recruitment is probably one of the most important functions of a "Respite Coordinator" (agency, person) and sometimes one of the most difficult. Use of all the media, public speaking, flyers, notification of doctors, clinics and other professionals discussed under the publicity section. Word of mouth in our rural area is one of Las Cumbres' most successful methods of recruitment. Families are asked if they know of someone who might be interested in being a provider. Often, in this geographic area, extended family members become official respite providers for families, enabling a more official relationship in the family receiving respite than a "favor" situation. For example, a mother or father with a disabled son or daughter might be reluctant to ask a relative to provide respite on the spur of the moment, or for extended periods of time as a favor, but might feel more free to ask when the relatives get paid.

In our more rural counties, our greatest success in recruitment is through contacts families already have. Providers may also know other persons who would be interested in providing respite – let them know when you are looking.

Train Providers

Recognizing the importance of training of providers, Las Cumbres also considered factors specific to the regions that we serve in developing our Provider Training model. In these rural regions, providers are often extended family members only wishing to provide respite for their own relative, and not wishing to receive training to provide respite to other clients. Some providers do not read or write and many are Spanish speaking providers who do not speak or understand English fluently. Our task was how to improve the quality of respite through training while still empowering families through supporting existing cultural and family structures which were working in the provision of respite and, without which, respite could not effectively exist. Because of strong cultural values and customs, many of these families would not use respite if this required going out-side the extended family circle. Many providers would drop out of the program if extensive and/or sophisticated training were required.

Las Cumbres therefore developed a three-tier Training Model. Providers are paid differential rates based on their level of training and/or experience.

Level I providers are family members (grandmothers, siblings, aunts/uncles) who, typically, have known the family for an extended period of time and are aware of the family's needs. The pay for Level I providers is $4.00 per hour. The family will typically waive our reference checks and the negotiable training requirements for these family members. The very minimum amount of training a related provider can receive is a two-hour, 1:1 session with the Respite Supervisor and eight hours of CPR and/or First Aid. In the session with the Respite Supervisor the following topics are covered:

- Purpose of Respite
- Incident Reporting

- Behavior Management
- Abuse and Neglect
- Death of a Client

Medications

Annual Meeting and/or Strength and Needs

Forms
- Provider/Parent Agreement
- Vouchers
- Agreement with LCLS

Level II providers meet all Level I requirements and either complete 40 hours of provider training or have a Bachelor's degree in a related field, or have three years' experience working with people who are developmentally disabled, or have 40 hours of documented specialized training. The pay for Level II providers is $4.75 per hour.

The 40-hour LCLS Level II training includes all the topics listed under Level I training and in addition consists of the following topics:

Introduction to Development Disabilities
Behavior Management/Positive Discipline
Rights
Home Safety
Normal/Special Development
Confidentiality
Parent Panel Presentation
Body Mechanics (transfers, positioning)
CPR/First Aid
Disabling Ourselves (an experiential exercise)
Rules and Forms
Death and Dying Issues
Teaching Self-Care Issues
Guardianship
Cultural Awareness
Infant Motor Development
Language/Speech of Infants
Nutrition
Sexuality
Communication Skills
Specialized Family Training

We have approximately 70 hours of trainings available (listed above). Seventeen hours are required and the provider selects topics that interest him/her to fulfill the 40 hours required. The format for these topics includes group process, videos, reading materials and individual work with the family the provider will be providing respite for. Las Cumbres sends to all Level II and III providers notices of in-service trainings that might benefit them in their provider role.

Level III providers meet and maintain all Level II requirements and provide respite to at least two LCLS respite families. The pay for Level III providers is $5.50 per hour.

The Specialized Family Training is given to the provider directly from the family around the individualized needs of the disabled family member. The purpose of this portion of training is to minimize disruption of family/client's routines and for the provider to be able to meet any specialized needs the client may have while respite is being provided. The family arranges the time for this training. Las Cumbres staff reviews with the family during their application for respite services what specialized needs their disabled family member may have and what a respite provider will need to know about usual routines, etc. The family may also request that the provider observe their family member in his/her classroom, day program, therapies, or other setting to get a better feel for the client and how to work with him/her. This observation time is counted as part of the two-hour family training. A provider who is not related to the family must complete Family-Based Training for each family for whom s(he) provides respite.

The two hours of agency-based training must also be received by the provider prior to providing respite for the first time. This is done either one to one or in small groups and led by the Respite Supervisor.

Only while developing the model, we offered stipends ($25.00 for a half day or training) to providers who attended Level II Training. Many providers who attended this Level II Training were family members of respite clients and unwilling to provide respite for clients other than extended family members. One major incentive for their attendance seemed to be the stipends we offered for coming. While these providers are valuable resources, the pool of trained providers from which we could draw was not

significantly increased as a result of training. From this experience came the decision that to achieve Level III status, providers must provide respite to more than one family. Extended family members or one-family providers may still attend any trainings offered.

In Las Cumbres' Model, all providers were strongly encouraged to attend their respite client's annual Interdisciplinary Team Meeting (IDT) (agency based) or EA&R meeting (if the respite client is in school) or their annual Plan of Care Meeting (if the client is Medicaid Waiver funded). Providers are paid at their usual hourly rate to attend these meetings. An average of about two hours per meeting could be estimated. Respite provider attendance at this (these) meeting(s) facilitates further training of the provider in client needs and also integrates respite services into other services which the client might be receiving.

Conclusion

The information above is a small sampling of rural-specific portions of the Las Cumbres "How To Start A Respite Program" manual. The entire manual is available for $30.00 from: Las Cumbres Learning Services, Inc., Respite Program, P.O. Box 1362, Espanola, NM 87532, (505) 753-4123.

The development of this manual was funded by a grant from the New Mexico Developmental Disabilities Planning Council.

PERSONAL ASSISTANCE FOR INDEPENDENT LIVING

John H. Gordon, Agency Director
Helen King, Assistant to the Director (Presenter)

Resident Services - Foundations of Senior Health was established to create a comprehensive, well organized, and flexible approach to service delivery. The program is comprehensive in that it offers a range of services to meet the needs of the consumer; well organized, because it is highly coordinated and based on standardized procedures; flexible in adapting to individual situations and to the differing levels of needs and abilities of the population. The program has brought all levels of government together to coordinate resources and planning. The private sector also participates in this process. On the state level, Rhode Island Housing serves as the coordinating agency, and State departments that provide human services have a role in program planning, operations, and funding. The program fits into the existing network of health and human services, filling in the service gaps that the consumer experiences as a result of bureaucratic processes.

On the governmental level, the result of intergovernmental cooperation is enhanced efficiency and effectiveness in providing services.

For consumers, the program has created a living environment which provides services to support their physical and emotional stability, while enhancing their quality of life. Through the program and Resident Service Coordinators' efforts, consumers receive on-site services such as: homemakers/home health aids, health maintenance and education, employment training, financial management, nutrition programs and meals, counseling and consultation, public assistance, and information and referral services. Although the services are available to the entire population, only 56 percent of those eligible have accessed available services. However, this 56 percent represents an increase of 42 percent.

The implementation of on-site Coordinators for management companies has resulted in more effective and efficient maintenance and resident

management. Coordinators intervene when social services are needed, eliminating any burden on management personnel who are unequipped to manage social problems.

Traditionally, housing management concentrates on the physical plant maintainence and repair. At first, owners and management were reluctant to become involved in social support services. By showing owners and management the benefits, especially cost-effectiveness, we were able to overcome their resistance.

Also, management was concerned about the legal liability of providing additional services. To overcome this concern, Rhode Island Housing, not the management company, contracts with the providers of the services and requires provider agencies to have liability insurance.

Clients are very-low and low income families, elderly, handicapped and disabled persons residing in Section 8 housing developments regulated by Rhode Island Housing. Of the 9,627 units in the portfolio, 86 percent of the units are occupied by a person living alone. Ninety percent of the residents fall within the very-low income category (income < 50 percent of median). Average eligibility income is $8,945 yearly. Seventy-nine percent of the units house elderly residents. Average age of the elderly residents is 74.1 years; average age of residents requesting support services is 72 years. Eleven percent of the residents are minorities, and 14 percent of Rhode Island Housing residents are physically or mentally handicapped/disabled.

The program currently services 56.2 percent of the population. Current research data shows that an additional 20-30 percent of the residents fall into the "gap" area the Resident Services - Foundations of Senior Health Program serves.

The Resident Services Program is currently implemented in 72 multi-family and elderly housing developments. Twelve of the elderly developments currently receive additional services (i.e., on-site homemaker services) under the Foundations of Senior Health Program. Total population of these 72 developments is 9,250 residents. The 24 Resident Service Coordinators, hired by the management companies, serve an aggregate 5,200 residents.

Unexpectedly, the Program has had significant impact on the population far beyond those persons receiving services. In Rhode Island, nearly 14 percent of the State's population is over the age of 65, compared with 11.3 percent nationally. Approximately 4.75 percent of the State's elderly reside in housing within Rhode Island Housing's portfolio. Most of the elderly have adult children who, although employed full- or part-time, are expected to provide care and supervision for their aging parent(s). Sometimes a family member must take an unpaid leave or quit his/her job to care for an ill or injured person. The Program provides for the practical daily supports that can give family members peace of mind and avoid disruptions to employment.

For more information contact Rhode Island Housing and Mortgage Finance Corporation, 60 Eddy Street, Providence, RI 02903, (401) 751-5566.

MEETING THE CHALLENGE OF INTEGRATED CHILD CARE

Sarah Mulligan, Project Director (Presenter)

The Educational Home Model (EHM) Outreach Project is designed especially for child care providers in rural areas who are interested in expanding their programs to include children with developmental, medical, or physical disabilities. Funded by the U.S. Department of Education (Early Education Programs for Children With Disabilities), the EHM Outreach Project uses both existing community resources and project resources to provide training and technical assistance to family day care homes and child care centers.

One of the project's primary goals is to increase the number of child care options for families of children with disabilities. In collaboration with local and state agencies, the Educational Home Model Outreach Project staff help to recruit, train, and maintain a network of integrated child care programs, including family day care homes, child care centers, private preschools, and Head Start programs. The model has been developed in rural and remote areas and includes specific adaptations for young children with multiple and severe disabilities and/or chronic illness.

Training and technical assistance is available to child care providers and administrators, early intervention specialists, families, paraprofessionals (including respite care providers and teaching assistants), and other individuals or agencies interested in integrated child care. The Educational Home Model Outreach Project resources are available to those interested in replicating the model, as well as those interested in exploring individual components of integrated child care. Written materials, current annotated resource lists, videotape exchanges, workshops, training sessions, on-site demonstrations, and telephone consultation via our toll-free number are incorporated into the training model.

There are essentially four phases that comprise the training activities of the EHM Outreach Project: identifying the target population, developing a local resource network, providing training and technical support, and conducting follow-up activities. These phases describe, in sequence, the steps project staff take to make sure that our efforts are truly responsive to local community needs and that there will be a long-term community impact.

By first identifying the target population in a particular community, project staff are able to specifically direct training sessions to the needs of a particular audience. In some geographic areas, this population consists primarily of family day care providers. In others, families as well as school district personnel participate. Although the training activities address skills and strategies specific to integrated child care, caring for children with disabilities in child care is a community concern and it makes sense to involve a variety of players from the start.

Within the geographic area, Educational Home Model Outreach Project staff identify a core group of child care programs to serve as a base for further training efforts. This core group includes child care providers working in family day care homes and child care centers as well as administrators. These individuals meet as a group to learn from each other and to identify the role families and other professionals might play in supporting integrated child care. In its earliest phase, this network of child care providers receives a tremendous amount of support and encouragement from project staff, plus assistance in planning the content for scheduled network meetings. As the network becomes more firmly established, tasks such as planning meetings are accomplished relatively independently. It is at this stage that many community professionals begin to see the impact that integrated child care has on the services they provide and child care professionals begin to see the value of community coordination. As a strong network of care providers begins to emerge, the promise of integrated child care also emerges.

Providing training and technical support, the third phase, is the heart of the Educational Home Model Outreach Project. The overriding principle of project staff is simple–child care providers already have many of the skills they need to care for a child with a disability; our job is to increase the providers' confidence in their own abilities while increasing their competence in working with children who have disabilities. The seven project components include a variety of awareness and skill-building activities:

Developing integrated child care programs for young children

Developing an individual program philosophy that addresses the unique characteristics of an integrated child care program includes learning to balance the needs of children with disabilities with other child care responsibilities, communicating program goals to families, responding to questions and concerns about integration, and assessing staff strengths and needs.

Meeting the individual needs of children with disabilities

Understanding how to incorporate each child's learning themes into caregiving routines is one of the most important elements of the training and technical assistance provided by the Educational Home Model Outreach Project staff. A series of training packages on this component include these specialized skill areas: managing behavior, social interaction, handling and positioning, facilitating small group activities, arranging environments, accessibility, adaptive equipment, facilitating communication, In addition to providing skill-building activities, project staff help child care providers learn to ask the right questions to get the information needed to care for a specific child.

Arranging the physical environment

Carefully planned indoor/outdoor modifications of the child care program's physical environment can help a care provider manage the challenge of adaptive equipment and promote accessibility for children with motor impairments.

Managing health and safety

Because many children with disabilities also have greater health risks, attention to health and safety is critical in integrated child care. This component combines best practices for maintaining the "well" child in child care with special considerations to address the individual health care needs of children who are chronically ill and/or medically fragile.

Involving parents and families

Active family participation in selecting and maintaining a child care placement adds to the success of the child's (and the child care provider's) experience. This component addresses important aspects of family involvement which include selecting a child care program; forming partnerships between parents and care providers; designing intake procedures to include the family opinions, concerns and goals; and finding ways to share equipment, information and expertise.

Encouraging community coordination

Services provided in the child care environment are vital to young children with disabilities and their families, and efforts to coordinate these services are essential to making integrated child care work in any community. The project includes training to help the child care provider collaborate with other early intervention professionals in the community, prepare for transition from child care to preschool or other school settings, and participate with other service agencies in planning for children's individual developmental needs.

Managing an integrated child care program

A good integrated program is essentially a well-run child care program with a few important modifications. Project staff help child care providers manage the ongoing demands of providing integrated child care which include developing and modifying child care policies and procedures, maintaining licensing and registration standards, maintaining confidentiality, and developing a plan of continued professional development.

Training in itself only begins to prepare child care providers to care for children with disabilities. The fourth and final phase of the Educational Home Model Outreach Project includes several distinct follow-up activities that allow us to continue to support and nurture integrated child care programs. At the close of training activities in a particular geographic area, we conduct a focus group in which child care providers reflect on the training and identify what worked and what didn't, what additional resources and support are needed, the unexpected challenges they faced, and what they learned about children, families, and themselves. The community networks of other integrated child care programs lend continuing support as providers face new challenges. Child care providers are encouraged to continue to use project resources (including a toll-free number, newsletter, resource library, and written training materials) as well as local resources that will help them continue to increase both their competence and their confidence in serving children with disabilities.

Integrated child care is challenging, but the rewards and benefits to the child, the child's family, and the child care provider are truly worthwhile. The Educational Home Model Outreach Project is working to expand quality child care for children with disabilities by helping child care providers prepare for the intriguing challenge of integrated child care. With training and technical support from project staff and local community resources, integrated child care is a valuable option in the array of early intervention services.

For more information contact the Educational Home Model Outreach Project, Montana University Affiliated Rural Institute on Disabilities, 52 Corbin Hall, The University of Montana, Missoula, MT 59812, (406) 243-5467.

PEER SUPPORT

Connie Kramer, Agency Director (Presenter)

Vision Northwest was established to serve those experiencing severe vision loss as adults. The main purpose of the organization is to give these people the tools to help themselves. This is accomplished through a state-wide network of 34 peer support groups and through the information and referral services offered by a central office.

Our consumers are adults who are experiencing severe vision impairment for the first time in their lives. Statistics indicate that in Oregon each year some 500 persons are declared legally blind and more than 1,000 experience vision loss severe enough to threaten their independence. Vision Northwest serves over half of them. Each year, we serve over 500 people through our program.

The program is innovative in both its scope and content. Only one other state, Massachusetts, has a peer support group, but it does not encompass the entire state, as does Vision Northwest. Groups located in rural areas have equal access to Vision Northwest programs and to information. Having all of the groups based on a peer-support structure is a creative departure from the usual model of professional leadership. One person in each group receives training through semi-annual workshops and is given program information and support throughout the year by phone calls and intermittent visits from the Program Director and Executive Director. In addition to an educational program at each monthly meeting, there is guided discussion about both the physical and emotional aspects of coping with vision loss. This exchange of ideas gives invaluable ongoing support to those experiencing this crisis. A final unique aspect of the program is that groups may dissolve after several months when the needs of members have been met.

One of the main obstacles that had to be overcome was physically reaching the target population of those new to visual impairment.

Once they had been reached, the next obstacle was, and is, to get persons in crisis to attend support group meetings. As the recognition of Vision Northwest has grown, these obstacles have diminished. However, recruitment efforts are consistently maintained. The other major obstacle was to garner a source of funding in order to set up and maintain a central office, staff, and to give ongoing support to the groups. This was accomplished by obtaining a major grant from the Meyer Memorial Trust. Sources of funding include fund-raisers, donations, grants, and corporations. We receive no federal, state, or United Way funding, and our services are free.

The Vision Northwest program of peer support groups has accomplished several major goals. Since its founding in 1983, hundreds of people have participated in the support groups. As the members of the current 34 groups come together to deal with their newly-acquired vision loss, they acquire hope, as well as a sense of independence and power in the face of what can be an overwhelming and terrifying situation. This is accomplished at each monthly meeting through practical applications, such as a demonstration of cane travel by a mobility instructor. An equally important part of this spectrum are the discussions on topics such as the grief experienced by those new to vision loss and the accompanying mood swings with which they and their associates must deal. On a cumulative basis, the program gives individuals a foundation for success as they once again become fully-functioning persons who live essentially normal lives.

Unexpected results have included the surprisingly great demand in areas outside of our population centers in the state of Oregon and the gratifyingly large group of volunteers who have become a vital part of Vision Northwest.

Although variations exist within each group, the program has been successfully replicated throughout the state. Attention to group leaders' training and frequent contact and support from the central office help maintain this standardization. We have had inquiries from several other states who are interested in duplicating the Vision Northwest program.

For more information contact Vision Northwest, 4370 NE Halsey, Portland, OR 97213, (503) 284-7560.

Support Systems

THE COMMON THREADS

Support systems include those services which are necessary for an individual to live and work as independently as possible. Services may be provided to an individual with a disability, to the family caring for such an individual, or to the staff members of disability service provider agencies. Services may include: respite care; personal care; home health care; chore services; homemaker services; child care; peer support groups; crisis networks; transportation; employee assistance programs; wellness programs; home modifications, and others.

♦ **Diversity breeds success.**

♦ Take care in portraying the need for help; don't exploit consumers by making them appear to be pitiful or helpless.

♦ Consumers are good networking resources. Establish support networks among people who share the same type of disability.

♦ Be responsive to a consumer's needs and wishes. Don't provide more services than are needed or wanted. Don't provide a high-tech, complicated solution if a low-tech, simple solution is preferred. Listen actively to the consumer. Be sensitive to attitudes, vocabulary, language, and level of comprehension. Allow enough time to find out what a consumer really needs and wants. Identify what "independence" means to each consumer. Train consumers in asking questions (ex.: train elderly people to ask questions of their doctors). Assure them that asking questions is appropriate and necessary. Ongoing peer training is important, but identify needs first. Focus on consumers' needs--this leads to **innovative approaches** and helps eliminate "turf" issues.

♦ Identify ways the service provision program can provide support services to other types of programs; don't always be on the receiving end.

♦ Access generic support services, such as homemaker services, by forming and maintaining a resource council with monthly information-sharing sessions.

♦ **Volunteers are crucial in times of tight funding: expand the capability of naturally-occurring, existing networks to provide support services; enhance their existing skills.** Consumers, consumer advocates, and peer support groups can contribute support services. Establish a volunteer action center and put out a monthly newsletter listing volunteer needs. Don't reject a source of support services just because it may mean rules must be bent or even broken. Take advantage of all government services (local, state, federal, and tribal). **Recruit civic groups, such as Sertoma, the Lions Club, the Elks Club, etc., to provide support services. Representatives of industry and business can serve on advisory councils of vocational programs and can provide, or sponsor, other support services.** Public schools and libraries, county extension services, students,

senior citizens' groups, and youth groups, such as Future Farmers of America, 4H, and Campfire, Inc., are also good resources. Look for unique, nontraditional special interest groups, such as the American Bikers Aiming Towards Education Motorcycle Club or dance clubs. Churches usually share the values of the community and can be powerful resources; they may be able to provide transportation and conduct health promotion activities. Look for unique resources in predominantly ethnic areas; Native American tribal associations are valuable resources in reservation areas.

♦ Don't come in as the "expert"; look for each volunteer's area of expertise. Provide adequate feedback for volunteer support service providers. Recognize volunteers (such as employers of transition program trainees) for their contributions. Provide recreational activities for volunteers; make volunteering a pleasurable, rewarding experience.

♦ Investigate the availability of National Community Service Act funds. This federal program will provide $250 million in grant money over a three-year-period for developing exemplary volunteer programs.

♦ Advertise and promote service provision programs through public awareness activities and media coverage. Politicians monitor the media. Use the media frequently and effectively; cultivate media acquaintanceships. Use "socially-responsible change" as a theme to recruit volunteers.

♦ Town cafes can serve as centers for sharing information on needs, recruiting volunteers, and getting referrals. Make stopping for coffee and conversation a priority.

♦ Sponsor and attend family-focused activities. Participate in or attend family-focused rituals and ceremonies (weddings, graduations, funerals, anniversary parties, etc.). Attend and participate in community-wide cultural and traditional events; use them as opportunities to raise funds and recruit volunteers. Become visible in the fabric of the rural community.

♦ Families need support services as much as individuals do. Family involvement in support services is crucial.

♦ Don't forget service provider staff have support needs, too.

♦ Train professionals to be sensitive when interviewing consumers. Educate professionals in the community about the immediate need for establishing support services for people transitioning back to the rural community from inpatient rehabilitation programs. Educate the medical community and develop cooperative ways to use their resources.

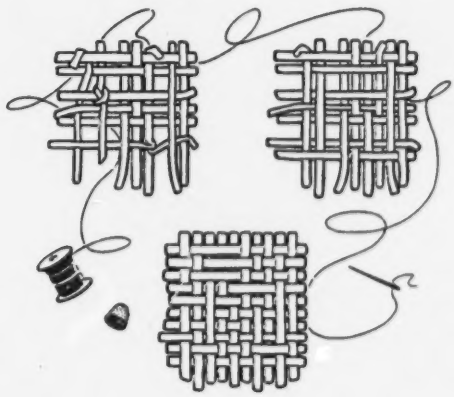
♦ Mental health services and support groups for people with developmental disabilities must be a priority. Crisis networks are a necessary support system.

♦ View the Americans with Disabilities Act as an opportunity for networking and for service providers to consult with businesses and municipal governments.

♦ Encourage international cooperation in areas bordering Canada and Mexico.

♦ Take advantage of current technology; use video and telephone conferencing; network with computers.

Small Group Facilitators: Mike Jakupcak, Sue Toth, Phillip Wittekiend, Shawn Clouse, Steve Dalin (Rural Institute on Disabilities), Mike Mayer (Summit Independent Living Center, Missoula).



ACCESSIBILITY

USING INTERACTIVE TELEVISION TO PROVIDE AND EXPAND RURAL SERVICES

John Pinter, President (Presenter)

In 1989, the Easter Seal Society of Utah (ESSU) received a grant from The Robert Wood Johnson Foundation to develop the **Rural Early Intervention Program (REIP)**. The purpose of the program was to provide early intervention services via interactive television in four remote, rural sites where services were difficult to deliver.

The basis for the service was the Utah Education Network's (UEN) EDNET television system. This television system connects outlying service sites, generally community colleges, area vocational centers or high schools, by microwave transmission with the lead site at the University of Utah, Salt Lake City. Microwave television transmission, which directs signals between "line of site" towers, allows simultaneous incoming and outgoing communication between an unlimited number of sites on the system. For example, as a speaker leading the group is speaking in one site, individuals participating at another site can interrupt with a question; at the same time, all sites can receive visual transmission from that site.

The UEN is primarily a delivery mechanism for classes or other educational activities. It has also been used in the past for conducting meetings, but its use as a regular direct service method has been relatively untested.

The basic objectives of **REIP** were:

1. To provide early intervention services, including physical, occupational, and speech therapy, and parent education, to 40 families with disabled children, aged birth to three, in rural Utah;

2. To provide trained home visitors to meet with families and provide program and therapy continuity; and,

3. To demonstrate the program and cost-effectiveness of EDNET to provide service in hard to serve areas.

These objectives were developed to address the critical shortage of therapy professionals in Utah, particularly in the rural areas of the state. The State Health Department provides a rotating assessment team of professionals from the three therapy disciplines three to four times per year and early intervention services in several parts of the state, but services are still in great demand.

ESSU selected service sites with the assistance of the State Health Department, based on known clients and shortage of services. In order to keep the number of people at any one site manageable, it was determined that four sites with a capacity of ten families would be chosen.

The four original communities selected were Roosevelt, Cedar City, Ephraim, and Richfield, Utah. These four towns represent a geographical range throughout the state, and generally are small cities of 5,000 to 12,000 residents in both town and surrounding area. After the first nine months, the site in Ephraim was dropped and service offered to Saint George, Utah.

Project management was provided through the supervision of the agency's director and an approximately 20% FTE contract director. This director was a speech pathologist (SLP-CCC) working as an individual contractor. She supervised therapy staff and home visitors, and planned the sessions and special presentations. Additional support came from another ESSU staff member, who provided continued supervision to home visitors between sessions, and family contact as necessary.

Easter Seals does not have therapists on staff, and contracted with an occupational therapist and physical therapist from Primary Children's Medical Center in Salt Lake City. The speech pathologist was in private practice in Salt Lake City. The therapist staff received training from the EDNET staff in how to best use the system.

Paraprofessional home visitors were recruited

from the communities which they served. These individuals included: the former director of a college based early intervention center; the mother of a disabled child; a special education teacher's aide; and a displaced homemaker. These individuals became part-time staff members of ESSU, paid generally between $5.00 and $6.50 per hour. Home visitors participated in a two-day training program with the program director and ESSU staff. Training included an overview of disabilities, orientation to the EDNET system and on-air practice, and training by the therapists.

Client recruitment was a shared responsibility of the Health Department, local public health nurses, and the home visitors. Because of client confidentiality concerns, families that the nurse felt would be appropriately served were given a brochure that provided a program referral. When the parent returned the brochure, ESSU staff would contact the family and determine eligibility. No fees were charged for the service.

Clients referred to the program were between newborn through age three. Most joined prior to turning three, but those whose third birthday occurred while enrolled were able to stay in the service. Disabling conditions included mental retardation, cerebral palsy, and others.

It was the intention of the program to have the therapist or program director conduct statewide individual client assessments. Client intake took much longer than anticipated, however, so assessments were obtained from the nurses or other sources. These provided for individual information about clients for the broadcasts.

Broadcast sessions were generally held every two weeks, for 1½ - 2 hours. A typical session was:

9:00 - 9:15 Welcome & orientation to session
9:15 - 9:45 Speech Pathologist
9:45 - 10:00 Occupational Therapy
10:00 - 10:05 Break
10:05 - 10:20 Finish OT
10:20 - 10:50 Physical Therapy
10:50 - 11:00 Wrap-up

Special sessions included "Adaptive Toys," by a rehabilitation engineer; "Nutrition" by the Health Department; "Parent's Rights: Individual Education Plans" by the state's parent to parent program; and a session on parent's needs by Kids on the Move Center, Provo.

During the session, the therapists demonstrated a technique with a child at the Salt Lake City site, and encouraged the parents to simulate the technique with their children, as appropriate.

Between the twice monthly sessions, the home visitors traveled among families to assist them in carrying out therapy goals and help them to find additional services. Families also received ongoing support and additional training. The therapists made two family visits per family during the program.

The program's grant period did not allow for sufficient public education time to better client identification. Public health officials weren't adequately informed on the program and its benefits. This was a major problem.

In addition, the State did not receive funding for expansion of early intervention services; service continuation would have required competition with early intervention center funding. Politically, this was an impossibility.

During the demonstration period, a total of 36 families were served in five sites. The total cost per session amounted to an average of $900 for two hours, including all staff costs, salaries and professional fees. This amounted to a cost of $23.50 per hour when fully staffed.

Parent evaluations reported a high level of satisfaction with the service; many indicated that REIP was the only service their child was receiving. Despite the distance between therapist and family, most were pleased with the program and the attention they received from the home visitor.

For more information contact the Easter Seal Society of Utah, Inc., 331 South Rio Grande St., Suite 206, Salt Lake City, UT 84101, (801) 531-0522, (801) 531-0575 FAX, (801) 531-9372 TDD.

ACCESSIBLE TRANSPORTATION

Linda Tonsing-Gonzales, Agency Director
Sharon Swanson, Rural Specialist (Presenter)

Raton is a small community in northern New Mexico with a population of approximately 8,000 people. New Vistas Independent Living Center which works with all disability groups, has provided outreach services to Raton since 1981. In 1987, the NVILC was awarded a grant from the State Division of Vocational Rehabilitation to establish an office in Raton and provide rural employment-related services. As the program progressed, it became clear that accessible transportation to and from jobs developed through the Rural Employment Services Program was a major need. Working with consumers on an individual basis did result in one quadriplegic acquiring a lift-equipped van from DVR, but community-wide advocacy was needed to address the issue of transportation. A lift-equipped van that could be used by the entire community was needed, not just for transportation to jobs, but for any travel within the area.

While it is not unusual for a non-profit organization to apply for UMTA (Urban Mass Transportation Association) funds to purchase vehicles, New Vistas Independent Living Center needed to ensure that should its Raton/DVR funding end, a van would still be available to the community, even if an NVILC office wasn't.

Other ILCs with home offices located far from their rural catchments might consider NVILC's solution to the community-based van dilemma. The NVILC Raton office staff person canvassed the community for a local agency or group that would join in a partnership to apply for UMTA funds. The search identified the First Methodist Church, whose congregation needed a van to transport parishioners to Sunday services. Using the NVILC grant-writing expertise and the Church's commitment to provide drivers and insurance, a grant was written for a 15-passenger lift-equipped van in April, 1989. NVILC also coordinated the fundraising for the local "match" funds needed (approximately $5,000) after the grant was awarded. This included a small proposal to the US WEST Foundation. The community was very supportive.

The van arrived in the summer of 1990. It has since been available to the community's disabled and elderly citizens for shopping, medical appointments, field trips, employment, social and recreational activities, or just for visits to friends or family members. On Sundays the van is used by the Church. While there may be no direct correlation with the purchase of the van, Rural Employment Services has placed approximately 40 people in jobs in an otherwise economically-depressed mining area of the State. With the increased ability of disabled people to work, and to move around the community in the van, their visibility has increased significantly. Their value as active, viable assets to the community is obvious. With approximately 1100 people with disabilities living in Raton, it is conceivable that all of them may use the van at some point in their lives. The community's awareness of people with disabilities has grown accordingly.

This program has not been replicated, but as was anticipated, DVR funding ended, though Center money still funds the Raton office on a 20-hour week basis. The van is in place. The percentage of the potential clientele who use the van service is difficult to calculate. Since the service merely increased a community resource, the riders may or may not be NVILC clients.

Now that the program is established, the annual budget for operation is the responsibility of the group or organization that holds title to the van -- in this case, First Methodist Church.

Daily operating costs have forced the Church to impose a rider's fee on the van service. While such a fee is not unusual, NVILC staff are seeking ways to access city/county resources for offsetting operating costs to make the rider's fee reasonable and affordable to all. A subsidy or reduced-fare coupon program is being investigated.

The van has become quite popular in the community and provides service to other groups such as Special Olympics participants, Boy and

Girl Scouts, 4-H Club, ministry to the homebound, and nursing home residents. This broad-based usage of the van demonstrates how communities can come together for a common cause that benefits all and fosters integration, rather than a having segregated "special" van for disabled folks.

UMTA reviewers were so impressed with the project justification, they would have funded two vans if the community could have financially supported both! Unfortunately, we had to refuse the offer.

For more information contact New Vistas Independent Living Center, 2025 South Pacheco, Suite 105-A, Santa Fe, NM 87505, (505) 471-1001.

ACCESSIBILITY OF COMMERCIAL AND PUBLIC BUILDINGS

Timothy Larson, Agency Director
Bobbie Bouvier, Program Supervisor/Counselor (Presenter)

In the spring of 1989, the Center for Independent Living of Northeastern Minnesota (CILNM) began a successful accessibility project to heighten community awareness, responsiveness and ongoing commitment to the removal of physical barriers.

Our project, a community access survey and guide, is clearly not original. However, all aspects of the project, including planning, process and results, represent a distinct departure from standard access guide production. Our objective was to use the end product as the means to attain the broader goals of public education and a shift in attitudes concerning accessibility requirements.

The most significant aspect of Access Hibbing is the decision to avoid labeling any facility "accessible" or "inaccessible". The guidebook contains only factual information, painting as thorough and accurate a word picture of site/facility conditions as possible. Since economic development is a key issue in our region, we used this feature to market the project. This approach results in an array of ongoing, exciting, community-based accessibility initiatives.

In terms of community awareness and receptivity, the assurance of a "positive" presentation and post-survey feedback/technical assistance made virtually all businesses in the community not merely willing, but eager, to participate. We are aware of only one refusal to permit surveying out of nearly 200 sites contacted! Volunteers were well trained, not only in the technical aspects of access surveys, but in critical community relations and education components. Business owners were given practical suggestions for improvements, statistics on numbers of those directly affected by improved access, referrals for additional technical assistance and information on available tax credits. The Chamber of Commerce, service organizations, city government, the city building official and community newspapers were "recruited" early in the process, giving community "ownership" to the entire project.

From the consumer standpoint, the guidebook format fosters increased independence, since guidebook users evaluate the available options for themselves, based on complete and accurate information. Thus, the decision concerning the accessibility of an establishment belongs to the individual, rather than the surveyors.

In February of 1990, as a direct result of Access Hibbing, the Hibbing City Council passed a resolution making a commitment to become a barrier free community. To that end, a community Access Advisory Council was formally recognized by the city the following month. The majority membership on the Access

Council is persons with disabilities. This group has cosponsored an ADA Information Workshop and a local Access Achievement Awards celebration, recognizing "usable" local businesses and services. They are spearheading a variety of community access improvements, including major renovations to the city arena/recreational facility, prioritization of sidewalks for curb ramps and the construction of a ramp between the regional hospital and adjacent shopping mall. Council members are also working with the public library to catalogue access resource materials, which will then be made available to the public through the library system.

One of the most unexpected results of the project has been the discovery that the city building official is a tremendous access advocate and resource. He has assumed a leadership role in Access Hibbing projects, initiating an upcoming accessibility workshop for plumbers and carpenters. This program component should have a significant impact in rural areas, where -- unlike urban settings -- design for most renovation projects, and often for new construction, is undertaken by general contractors/tradespeople. Enhancing the access education of design professionals appears to have minimal impact on accessibility in rural America.

We are currently involved in assisting three communities in northeastern Minnesota to replicate this program. In each of these towns volunteer "steering committees" are adapting our model to meet their individual community needs and priorities. In conjunction with the Multiple Sclerosis Society, we are developing a statewide program called Community Access Partnerships which will provide standardized training materials, survey tools and resources to rural communities. A community access coordinator will be based in each CIL to facilitate project objectives. Our presentation of this project at the Region V Independent Living Conference (October 1990) has resulted in additional inquiries from as far away as California and Nevada.

CILNM serves persons with all disabilities, as does the Access Hibbing project. A recent Wall Street Journal article cites 43% of the population as DIRECT beneficiaries of access improvements. Based on the recent census, 8600 individuals are potential recipients of project benefits within Hibbing city limits. Approximately 1800 copies of the guidebook have been distributed to date through area service providers, Chamber of Commerce, tourist attractions, county information and referral agencies, libraries, health care providers, etc. However, we believe that the project impact has been, and will continue to be, much broader. For example, the project recently worked with an area grantor to incorporate accessibility requirements into their funding guidelines. This agency provides grant monies for physical plant improvements in more than 200 rural communities. (Total population of this area is approximately 150,000, spread over 13,470 square miles.)

The project did encounter obstacles along the way. Since our approach to access surveys and guidebook production was unique, we encountered the practical difficulties of developing appropriate training methods and materials, survey tools, "marketing" strategies and informational pieces. In short, we lacked the forms to fit the intended functions.

However, our most difficult obstacle was the project goal itself. A frequently heard axiom concerning accessibility is that attitudinal barriers are the most difficult to overcome. The Access Hibbing project was designed and carried out to address this issue. Under the "guise" of producing an access guidebook, our project is working toward shifting attitudes concerning accessibility requirements, from something "they" are making us do "FOR THEM", to something which is of tangible benefit to the whole community. We are convinced, for reasons which we have outlined here, that we have made great progress to overcoming this obstacle, which IS our ultimate goal.

For more information contact the Center for Independent Living of NE Minnesota, 2310 First Avenue, Hibbing, MN 55746, (218) 262-6675 or (218) 254-5757.

AFFORDABLE AND ACCESSIBLE HOUSING

Duane French, Agency Director
Bill Crandall, HAMMER Project Coordinator (Presenter)

The HAMMER Project provides accessibility modifications to private homes at an affordable price.

Its most innovative aspect is the partnership between the local carpenters' unions and Access Alaska. Prior to HAMMER, persons in Fairbanks who needed modifications to make their homes more accessible were forced to figure it out for themselves. Many were unable to bear the expense of costly home modification, and in the worst case scenario, would just not leave their homes. People living in institutions or with their families were not able to find accessible housing to move into. Access Alaska began hearing from these families and initially asked for public funding to pay for the materials and labor to meet their needs. Funding sources endorsed the proposals but claimed the number of people who would benefit were too small to justify the money requested. Rather than give up, Access Alaska met with the local carpenters' union manager to discuss the need for accessibility modifications for people who were 'trapped' in their homes. The manager felt that the local carpenters would be willing to donate their expertise. To motivate them, he offered to move their names up on the call ladder for paying jobs if they would help out in this community project. Access Alaska then approached the local chapter of Easter Seal and received a small grant of $2,000 to help purchase building materials to modify homes. In addition to this grant, Access Alaska asked for discounts from the local building suppliers to help stretch the small amount of money we had received. From this merger of the not-for-profit sector and the local labor pool, Access Alaska began the program of remodeling existing homes.

Since 1985 HAMMER has not received funding in excess of $2,500 from any one source. People who request services from this program have been asked to contribute to the fund if possible, and small donations from large corporations are solicited annually to be used for purchase of materials. This "revolving fund" method has kept the project operating as Access Alaska continues to seek a more permanent source of revenue.

The greatest obstacle to increasing the number of people served by the HAMMER project is the availability of union carpenters. Alaska has a short building season due to weather, and since the project utilizes volunteer labor, people who need outdoor modifications must wait until the work demand on union carpenters is not as great. Unfortunately, that is the time of year (summer) that Access Alaska receives the greatest number of requests. Access Alaska also recognizes that advertising this project would only serve to increase the waiting list. There are only so many carpenters willing or able to "donate" their time.

Since 1985 when the HAMMER project was conceived, Access Alaska and the local carpenters have provided accessibility modifications to over 60 private homes. The individual projects include: building entrance ramps, widening doorways, adding grab bars,
providing adaptive hardware (sinks, door handles), and providing remodeled kitchen areas for wheelchair users.

One unexpected result of the HAMMER project has been that the staff person coordinating the projects has become the community "expert" on accessibility and is now called upon to provide technical assistance to private and public business.

The HAMMER project has provided modifications to many age groups and to people with different disabilities. The most common disability has been a mobility restriction requiring adaptation of the physical environment. The project is currently able to meet approximately 60 to 70 percent of the 20 to 25 requests it receives annually for some type of modification.

For more information contact Access Alaska, 3550 Airport Way, Suite 3, Fairbanks, AK 99709, (907) 479-7940.

Accessibility

THE COMMON THREADS

Accessibility is the availability of a person's environment. It is a measure of the ease and safety with which a person can perform the tasks, and experience the pleasures, of daily living in his/her home and in the community.

♦ "Accessibility" has different definitions across age groups. **Accessibility is a community issue. Everyone has general accessibility needs; some people have specific needs.** Accessibility can have physical, attitudinal, environmental, and cultural definitions. Environmental inaccessibility due to pesticides and other toxins is a growing problem (ex. mobile home components may contain formaldehyde). Transportation is limited or difficult for non-drivers, especially those with mobility or vision impairments. Sensory access is important for those with hearing or visual disabilities; hearing dogs, seeing-eye dogs, wind chimes on farm outbuildings, telecommunication devices for the deaf (TDD's), flashing alerts, cellular phones, and wave sensory systems are solutions. Language can limit access; some rural areas, especially in the U.S. Southwest and those near reservations, have populations speaking two or more languages. Bilingual signs may be a small way to increase access to businesses and public services. Different program areas mean different access problems. Take a total environment approach.

♦ **Information access is also important;** use toll-free pnone numbers, telecommunication devices for the deaf (TDD's), computer networks, public libraries, "Ask a Nurse" lines, state developmental disabilities advisory councils, and state legislature information offices. Use "road shows" to take program information out into service areas. Computers can make speech "visible" and can be activated in a number of ways without typing; they can facilitate communication between people with disabilities. The Pacific Northwest Augmented Communication Group and similar organizations are resources for communication solutions. Many states now have telephone relay systems which connect telephone callers with hearing impairment with hearing callers: the caller dials an 800 number; the call is relayed to a TDD or from a TDD to a telephone. The service will be available nationally in two years.

♦ **Demonstrate creative accessibility solutions,** like Alaska's "HAMMER project". Use commonsense solutions and share them. Encourage judges to sentence minor offenders to community service making accessibility modifications. Explore using work-for-credit approaches, such as Food Share uses. Use Vista volunteers, the National Corps of Retired Executives, and other groups to make modifications, advise on financing, and acquire materials. In remote areas, where even roads may be nonexistent, accessibility solutions have to be personal and individualized.

♦ Use the expertise of university rehabilitation engineering units. Architectural schools, vo-techs, and high school shop classes can be centers of education and technical assistance for making accessibility modifications.

♦ "Comprehensive Housing Affordability Strategies" groups are forming to fund accessible housing in innovative ways. Look for creative ways to fund housing, modifications, and transportation. There are private funds with no strings attached, state transportation funds, community block grants, United Cerebral Palsy Association loans, vocational rehabilitation monies, Farm Home Administration loans, etc. Look for unique transportation solutions; use county resources or fund vehicle-owners to provide transportation.

♦ Take a proactive, positive approach to the Americans with Disabilities Act requirements; enlist the cooperation of key decision-makers in the community. Emphasize that compliance has positive economic results--people patronize accessible businesses. Reward and promote businesses that take the initiative to become barrier-free. Avoid becoming the "accessibility police". Be flexible when asking for reasonable accessibility accomodations. Build on the ADA requirements. Regional Disability Business Accomodation Centers will help businesses with accessibility problems, but most centers are in urban areas and oriented toward employers with 15-25 or more employees. Most rural employers have fewer employees; accessibility is the major rural issue. Each area will have an advisory committee; rural areas should strive for representation, so rural accessibility will have equal importance with jobs.

♦ "Program accessibility" is necessary--once the consumer gets in the door, is the program really worthwhile and appropriate? Programs must be tailored to the individual's needs and wants, rather than taking a "cookie cutter" approach.

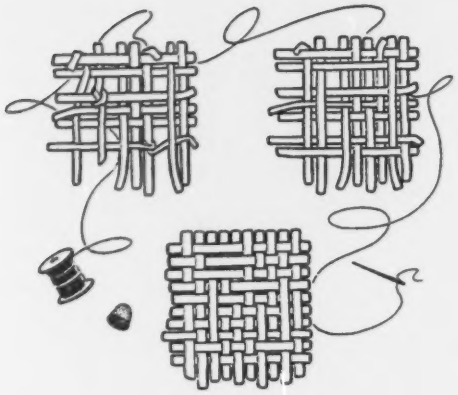
♦ People with disabilities frequently lower their expectations and adapt to inconveniences; help them recognize problems and explore possible solutions. A consumer's experiences can be valuable awareness lessons for the public. Ask consumers for ideas on establishing access.

♦ Educate policymakers, teachers at all educational levels, and the general public about accessibility needs. Survey community housing and transportation needs and use the figures to educate the public. Let people experience accessibility problems firsthand. Present a consistent message and be prepared to regroup when attitudes don't change. Pursue political change locally, statewide, and nationally. Use the local media to best advantage.

♦ Pursue curriculum changes in architectural and engineering programs. Educate architecture students on architectural barriers.

♦ Mobile homes fill a rural housing need, but need modifications and adapted construction techniques to be accessible. Develop a "road show" for mobile home occupants; educate them on barriers and possible modifications.

Small Group Facilitators: Mike Jakupcak, Shawn Clouse, Kathy Miller-Green, Tom Seekins (Rural Institute on Disabilities), Jude Monson (Summit Independent Living Center, Missoula).



INNOVATIVE RURAL INTERPRETATIONS OF DISABILITY LAWS AND PRACTICES

SPECIALIZED FAMILY CARE PROGRAM

Kaaren C. Ford, Medley Specialized Care &
Community Placement Program Manager (Presenter)

As a result of a 1981 class action lawsuit, Medley vs Ginsberg, the West Virginia State Departments of Health, Education and Human Services gained approval to work cooperatively to develop a statewide system of community-based services so young people living in state institutions could move into community settings. The Specialized Family Care Program was developed as part of these community based services. It is a comprehensive statewide placement and family support program serving individuals with developmental disabilities who have been, or who are at-risk of being, institutionalized.

The purpose of Specialized Family Care is to provide individuals with a home-like atmosphere where they can grow and develop to their maximum physical, mental, emotional and social potential. The program is based on the belief that all children and most adults, regardless of their disability, belong with families and need enduring relationships with adults. Specialized Family Care for the most part is a permanent placement. In some cases it is a short term living and training setting, a step toward moving back with the natural family or on to more independent living.

Individuals in placement are integrated into the communities in which they live as part of well functioning families active in their communities. These folks attend church, ball games, movies and school dances. They see local doctors and dentists, and purchase goods from local merchants. Specialized Family Care has helped change the service delivery system in our state. After ten years of community integration, our state has passed its first Family Support legislation so natural families can receive the community services needed to maintain their family members.

Specialized Family Care was initially developed to provide for the needs of Medley Class Members. It has, however, evolved to where it now serves non-Medley adults, as well as children at risk of institutionalization. Currently, there are a total of 228 individuals living in Specialized Family Care Homes throughout West Virginia. Specialized Family Care also provides respite services to natural families receiving Title XIX Waiver funding. A recent placement needs survey indicates that 370 individuals need placement and/or respite services.

Medley Class Members and Title XIX Waiver-funded individuals are targeted for placement through an interdisciplinary team process. In West Virginia the responsibility for placement and service delivery for individuals with mental retardation rests with the local interdisciplinary team. Core members include the case manager from a local behavioral health center, an advocate from a statewide agency and the Family Based Care Specialist contracted by the Office of Social Services, Department of Health and Human Resources.

When an individual is targeted for placement, the Family Based Care Specialist assesses his/her needs and decides if Specialized Family Care is appropriate. If so, the Family Based Care Specialist matches the individual with a provider.

The matching process involves assessing both the targeted individual's needs and the skills of the Specialized Family Care provider. Specialized Family Care providers are recruited to provide permanent homes for individuals with developmental disabilities. They get to know the targeted individual prior to placement; in many cases they are recruited to meet the needs of one particular individual.

Trial visits and individual-specific training are initiated once the match has been made first at the individual's residence, then in the Specialized Family Care provider's home. This gives the individual an opportunity to become familiar with the family, home and the community in which he is going to live. Trial visits and individual-specific training can take several weeks to complete. Placement follows.

Members of the individual's interdisciplinary team work together to ensure a stable placement. The case manager coordinates medical, education, habilitation, and speech services. The advocate monitors the adequacy of these services and addresses systems issues. The Family Based Care Specialist monitors the Specialized Family Care Home to ensure that it meets certification standards, coordinates or provides on-going training, provides support to the family, and acts, when necessary, as the family's advocate. This local interdisciplinary team develops the individual's service plan. The service plan or Individual Program Plan, is updated and reviewed every six months to reflect the individual's changing needs.

In West Virginia, the local community behavioral health centers contract with the Office of Behavioral Health, Department of Health and Human Resources to provide case management services to individuals with developmental disabilities. The Office of Social Services, Department of Health and Human Resources, is the state-mandated home finding agency. The Office of Social Services has home finding contracts with three agencies to certify families as Specialized Family Care providers. Advocacy services are provided by an independent statewide advocacy agency. Staff of the Medley Management Team coordinate these three services. The Medley Management Team is composed of the directors of various programs from the State Department of Health and Human Resources, State Department of Education, and State Department of Vocational Rehabilitation. This team is under court mandate to oversee services to Medley Class Members. The Program Manager of Specialized Family Care is housed in the Office of Social Services and is a resource on services to individuals with developmental disabilities. This Program Manager is an employee of the University Affiliated Center for Developmental Disabilities/West Virginia University, and serves on various UAC program committees. The Program Coordinator reports to both the Director of the UACDD and to the Director of the Office of Social Services.

Thirteen standards must be met before a family can be certified as a Specialized Family Care Home. The family's home must be safe and accessible. The family receives twelve hours of pre-service training and undergoes an extensive home study. The pre-service curriculum includes: background and overview of the Program; role of the Specialized Family Care parent; role of the respite provider; standards for approval of homes/performance contract; the definition of developmental disabilities; the DD bill of rights; the Education for All Handicapped Children Act; behavior management; developing self-respect; medication and monitoring; seizure disorders; nutrition for individuals with developmental disabilities, first aid; home fire safety; the normalization principle; and human sexuality. The family also receives Orientation to Medicaid Personal Care training and CPR and First Aid training. Certified families can be certified as Medicaid Personal Care providers and receive their own Medicaid Personal Care provider numbers.

Each certified family receives 32 yours of ongoing training each year. This includes individual-specific training, provider elective training and CPR certification, with First Aid certification every three years. All training except CPR and First Aid is documented by lesson plans with specific written behavioral learning objectives, training methods and evaluation methods. These lesson plans are reviewed by a Qualified Mental Retardation Professional and signed by the family. This training is done through one-on-one sessions, small groups, or workshops and uses handouts, hands-on training and multi-media materials.

The demand for, and interest in being, a Specialized Family Care Home varies from area to area of the state. Large statewide recruitment campaigns are not successful. Personal interest stories in local newspapers draw a great deal of interest, but word of mouth is the most successful recruitment method. Individuals who know, or who have seen, Specialized Family Care families are those most genuinely interested in committing themselves to the program. Most of our families live in small communities in which caring for others is common.

The Specialized Family Care Program consists of a statewide network of Family Based

Care Specialists who recruit, screen, train and certify families as Specialized Family Care providers. The statewide network of Family Based Care Specialists is directed by a Program Manager. The Program Manager holds monthly meetings with all the Family Based Care Specialists at which they receive group training. Of the 19 Family Based Care Specialists, 13 are housed in local area Division of Human Services, Department of Health and Human Services, offices. These Family Based Care Specialists are developmental disabilities resource persons.

The Family Based Care Specialist monitors the home monthly, then quarterly assesses whether the individual's needs are being met and submits annual recertification narratives for review and approval. The Program Manager reviews Specialized Family Care records and conducts on-site visits.

Specialized Family Care is an exemplary program in that:

- it is individual-focused and family-centered
- it provides permanent placement
- it is the epitome of community integration
- it is the best example of inter-agency collaboration in our service delivery system
- all placements receive respite services
- there is an interdisciplinary team approach to services
- all providers meet Medicaid Personal Care provider certification standards
- on-going training is formalized with lesson plans and posttests
- seven children in placement have been adopted since 1989
- there are 228 individuals (adults and children) in care with 218 certified families

For more information contact the University Affiliated Center for Developmental Disabilities, Chestnut Ridge Professional Building, 918 Chestnut Ridge Road, Suite 2, Morgantown, WV 26506, (304) 348-7980.

SUPPORTED EMPLOYMENT IN A RURAL SETTING

KrisAnn L. Carlsen, Administrative Assistant (Presenter)

Rural Employment Alternatives, (REA) Inc. is a private, non-profit agency that has provided traditional sheltered work services to adults with disabilities in a rural Iowa county for almost eleven years. REA has served approximately 35 - 50 consumers in work services. Consumers are placed in facility vocational tasks of clerical, assembly, and packaging, etc. and they work for a piece-rate wage. In 1988, REA began a supported employment program designed to place consumers with disabilities into integrated employment opportunities, with the ongoing support from a staff of job coaches. Currently, REA offers both sheltered work services and supported employment. REA and it's Board of Directors have made a firm commitment to provide supported employment to all of its consumers. It is REA's goal to totally convert from sheltered work services to providing supported employment for all consumers. This conversion has not been, nor will be without obstacles and growing pains, but it has its rewards for all people involved.

The onset of the program was met with opposition from various directions, including agency staff. The staff providing work services training placed a strong emphasis on accuracy of skills in specific segregated tasks. The facility was staffed with personnel with traditional beliefs; believing that what they were training was the best for consumers. In the initial stages of supported employment, the staff felt that supported employment would decrease the workforce in the facility to the extent that

contracts would not be completed in a timely and efficient manner. However, it has provided the opposite, an increase in consumer skills, both in the facility and in supported employment jobs. As individuals are placed in a community work site, other consumers have the opportunity to learn new skills within the facility. Without the movement of individuals into supported employment, this new training of skills would not have taken place.

REA began with one job coordinator, hired through a grant project with the local university, University of Iowa. That individual was responsible for the development as well as the coaching of job sites. In one year, REA had placed ten individuals in community job sites. Today over 50% (about 25) of the consumers served by REA work at individual community job sites earning at or above minimum wage.

Janitorial and food service opportunities were the most readily available placements. We developed sites that required anywhere from only two hours of work in a week to those that required 40 hours of work in a week. Those individuals that needed the most supervision and did not have the stamina for more hours of work, were placed in the positions with minimal hours. We have found that those jobs offering only a few hours a week are not cost effective. They require a greater percentage of on-site time from the job coordinator. And, after a year and a half of providing services to those sites, we gradually eliminated them. Like most agencies providing supported employment services, a creaming of the crop took place with our first placements. We were looking at getting our image changed from that of a traditional sheltered workshop to that of a community employment service for adults with disabilities, and wanted to put our best foot forward. Although the program has been offering employment opportunities in traditional "food and filth" positions, the agency is now attempting to diversify the job opportunities for consumers. Diversification in terms of the kinds of job opportunities, as well as the type of supported employment model offered. Of course, we are dealing with the general business community and rely on their employment needs.

Currently 99% of our placement sites are individual job settings. The greatest number of consumers served include individuals with mental retardation and mental illness. Other diagnoses includes autism, physical impairments, and dual-diagnosis disabilities. In an effort to place everyone, including those with severe disabilities and typically not placed in the community, REA will have to utilize other supported employment models in addition to the individual work sites. These models include: dispersed heterogeneous placement model, mobile crew model, and the enclave model. Because the agency believes that integration with the general work force is a critical issue, we have resisted developing enclaves or mobil work crews. These two types of models typically do not offer opportunity for the consumer to associate with other employees. In our efforts to get all consumers placed, we will be looking at the development of such models for those individuals for whom an individual site is not appropriate for their disability. It is a challenge that REA staff is willing to take on.

REA currently uses the Virginia Commonwealth University Rehabilitation Research and Training Center (VCU-RRTC) integration index to develop job sites that will offer the best opportunity for persons with disabilities to mainstream with their community. A potential job is rated and given one of the following scores:

1. Individual experiences no contact with non-disabled people other than service workers, immediate family members or volunteers.

2. Individual's contacts with non-disabled workers were incidental to their tasks and did not provide opportunities for the development of ongoing social relationships.

3. Ongoing opportunities to interact with non-disabled workers throughout the day in nonwork activities (breaks and lunches), but the assigned job tasks did not require direct interaction with other workers.

4. Opportunities to interact with non-disabled workers in work and work related activities on the job site.

5. Person has the contact with non-disabled workers within and outside the work site.

When developing a site we require that the integration be at least during breaks and lunches (#3). It is preferred that integration be a natural part of the job position (#4 or 5).

Another item that is considered when developing jobs is transportation. Transportation tends to be the largest barrier of supported employment and the development of job sites in rural settings. In an effort to develop a cost effective program model, consumers are placed in job sites of close proximity with comparable hours so that a job coach can support more than one consumer with less transportation time and expense. Our county transportation system has been willing to detour off of regular routes to accommodate us. Individuals have been placed into work sites in or near their home communities, all of which have a population base of between 900 - 2500. When developing opportunities in smaller communities the job possibilities need to be creative. Many businesses are small, locally run stores, that utilize only family employees. In most every community over 1500 in population, there is a manufacturer or larger business that requires a labor force. If appropriate job possibilities are not available in the consumers local community, we have developed them in larger cities in adjoining counties. We have had to tap into any commuting systems that may run from the smaller communities to a larger one, for our transportation needs. Parents, co-workers and other car pools are utilized when the job coordinator can establish them. As a last resort, REA will transport a consumer to or from a community job site.

The agency has worked over the last three years to obtain funding to expand our supported employment program. Grants have been secured by pooling efforts with other rural providers in surrounding counties. REA's initial grant from the University of Iowa was for the development of new placements for moderate to severe individuals to be placed into community employment sites. This "Coordinated Services Grant" allowed REA to hire one full time job coordinator. In November 1987, an advisory committee was developed to discuss possible strategies and barriers to placements. The committee consists of a diverse array of people: U of I personnel, REA staff, parents, employers, funding service providers, and school personnel. The committee meets 6-8 times annually. To date REA has collaborated with similar agencies and universities to receive funding and participate in a variety of grant projects including: The Association for Persons with Severe Handicaps (TASH), Iowa division of MH/MR/DD, Job Training Partnership Act, and Supported Employment Management Information Systems data base project through the Institute for Social and Economic Development. Grant projects have focused on the development of job sites, the expansion of hours on sites, the placement of more severely involved individuals, expansion of public relations, and providing technical assistance. This summer REA began a new program designed to place persons with severe/profound mental disabilities and physical disabilities into supported employment, using a dispersed placement model. Another opportunity will be REA's participation in Virginia Commonwealth University Rehabilitation Research & Training Center's "Natural Support Transitioning Project" when it is funded. VCU-RRTC and John Kregel are first-rate leaders in supported employment. This project will increase REA's reputation on a national level. Other efforts to diversify funding includes the development of PASS plans and IRWE plans for consumers receiving Social Security benefits. In addition, REA has received United Way funds for the program. With the recent stress on the state and local budgets, REA has determined that the more diversified we are in our funding, the more opportunities we will be to offer individuals with disabilities to gain community employment.

Ongoing funding has been maintained by redirecting facility-based resources into the supported employment program. The organizational table has been reorganized to include a mid management position in this program. In addition, we have reduced the number of in-facility staff and increased the number of job coordinators. Today we have 7.5 job coordinators for our supported employment program. All of the positions are classified as

coordinators but we have designated one individual to do job development only. Another two individuals do development and coaching, and the remainder are primary coaches. REA is adamant about keeping on the cutting edge with our supported employment program. We take advantage of all training opportunities that are available to our staff. REA has utilized regional training offered through the University of Missouri. We have certified coaches, trained management and have acquired a network of valuable resources through this participation. REA is dedicated to the training and continued education of all staff. There is a $300 allowance annually for staff to obtain credits for courses that further education. This allowance is in addition to the rehabilitation training in-services and conferences that REA staff attend. REA staff have also visited other successful supported employment programs around the country. They have brought back new ideas and insight into where we should be going.

With the recognition of our supported employment program on the local, state and national level, there has been an increase in referrals for the program. After the first year of supported employment at REA, an increase of 50% in numbers of referrals was obtained. We are now receiving referrals from the local school programs. Three years ago those individuals graduating wanted nothing to do with the services we had to offer. Surrounding counties are also referring individuals to our supported employment program. The expansion of our referral sources to neighboring counties has provided an opportunity for REA to develop a sharing system with other rehabilitation agencies. We have found that a joint effort provides for a strong system to approach employers with. A give and take understanding has been established between a pool of rural service providers. What we are all after is the same, community job opportunities for our consumers.

The outcomes for consumers served through this program have been dramatic in terms of financial earnings, friendships with non-disabled co-workers, and integration into the community. The program model supports job placements based upon consumer interests rather than a prerequisite skill level. Job coaches make an ongoing commitment to the consumer and business. Although, job development and placement in a rural setting is challenging in terms of employment opportunities, transportation, community perceptions, and other issues, it is a workable model that needs to be provided as an alternative to a segregated facility-based program.

REA's key to a successful rural-based supported employment program has been the communication and cooperation among all persons involved. Department of Human Services, Department of Vocational Rehabilitation, county transit system, University of Iowa, residential providers, parents, JTPA, and consumers all have been consulted when looking at providing a job placement for an individual. REA has been recognized as a leader in supported employment, the credit needs to be extended to all people who have worked with us.

For more information contact Rural Employment Alternatives, Inc., P.O. Box 24, Conroy, IA 52220, (319) 662-4043.

COMPLIANCE WITH P.L. 99-457 IN RURAL COMMUNITIES

Thelma Robinson, Pediatric Nurse Specialist (Presenter)

A new federal program has been created for infants and toddlers who have developmental delay and their families through the Part H component of P.L. 99-457.

A long-range goal is to reduce the need for special education and diminish the possiblity that children will be institutionalized. States have been challenged to: (1) develop and implement statewide, comprehensive, coordinated, multi-disciplinary early intervention services; (2) facilitate the coordination of early intervention resources from federal, state, local and private sources; and (3) provide quality early intervention services.

Immediately, questions arose from states with rural populations. How can quality early intervention services that depend on the facilitation of coordinated resources exist when there are only minimal services and often no services at all? Creative solutions would be necessary to meet the unique needs of the remote and rural population where a shortage of available personnel and resources exists. Although federal expectations seemed unsurmountable, the state of Alaska began planning in 1988 for the expansion of the present Infant Learning Program to comply with P.L. 99-457 for all infants and toddlers, regardless of where the children and their families lived. Several principles emerged regarding early intervention services for infants and toddlers with special needs and their families who live in rural and remote regions.

- The family, as defined by its community and culture, is the primary support system for infants and toddlers.

Children are dependent upon their families, which makes a family-centered approach essential in early intervention. The definition of family must reflect the diversity of family patterns and structures.

- Children and families are more responsive in familiar and convenient settings.

Community based services are essential. Infants, toddlers and their families are best served in their own homes and communities.

- Services are determined by the needs of the children and their families versus the availability of services.

Too often in rural communities needs of families are not met due to lack of services or service providers. New strategies for providing services would have to be developed in order to meet the needs of children and their families living in rural communities.

- Basic everyday needs for families hold priority over professionally devised schemes.

Inadequate housing and food, unsafe water, unemployment, lack of transportation, child care and health care may cause rural families concern. Early Intervention Programs must work closely with other programs to make certain that these concerns are resolved. Families can then turn their attention toward healthy growth and development of their children with special needs. Parents must become partners with professionals in developing the Individualized Family Service Plan or the plan will not be successful.

- Competent rural services reflect responsiveness to the uniqueness of the family and community.

Unfortunately, professional service providers may be insensitive to local cultures or communities. It is important to recognize that "differences" are not the same as "deficiencies." The professional must work hard to understand his/her own culture and at the same time respect cultural or community diversity.

Significant issues frequently encountered by the rural service provider include the following:

- Geographic isolation. It is difficult to maintain contact with families who live in hard-to-reach rural and remote areas and/or families who migrate seasonally to work in subsistence fishing and hunting or agriculture.

- Preference for folk medicine or traditional child rearing practices. Families may not readily accept western world concepts.

- Mistrust for professionals. Professionals have often over-whelmed families with professional jargon and ideas. Professionals may come and go so frequently that a trust relationship cannot be established.

Significant issues for rural program planners include:

- Burn out and attrition of professional staff.
- Local professionals lacking in specialized training.
- Time-consuming collaboration with other programs and agencies.

A number of action steps to assure that all families have access to adequate and appropriate services are in place. Other program needs have just been identified and strategies are in the planning phase. Various components of the law will be discussed in regard to practical, workable strategies for serving families in remote and rural regions.

Public Awareness

The following examples are strategies for promoting early intervention in rural communities.

A Russian "Old Believer" parent of a child enrolled in the Infant Learning Program wrote a pamphlet describing the services in her native language for the families in her remote fishing community.

A group of Athabascan parents got together and made posters describing a new Infant Learning Program. They advised the new teacher as to strategies that would best introduce services into their village. The parents suggested offering community classes in growth and development in order to emphasize the importance of developmental screening and early intervention.

A local radio station invited a statewide travel team visiting a hub arctic community to share information during a local talk show. They discussed the benefits of a multidisciplinary evaluation for infants and toddlers with special needs. After each team member reported on his/her specialized role, the information was translated into Inupiat by a well known native woman proficient in both English and the Eskimo language. This information was radioed to seven villages above the arctic circle.

Family Involvement

Family involvment is crucial. The following are examples of family participation.

Native American parents completing an evaluation form for a multidisciplinary clinic asked that coffee and doughnuts be served to help them relax for their stressful event. Parents are now telling professionals how services can be offered more effectively.

A committee on a Task Force spent months developing a coordination form for parents. When the form was presented to a panel of parents, the committee was told that the form was appropriate for sharing information but that they would not use it to give permission for services. The Task Force learned the importance of involving parents in planning from the beginning.

A parent was a team member participating in a national program for multidisciplinary evaluation teams. This team then trained other community-based evaluation teams throughout Alaska. The parents involved in this national and state team training effort gave new insights as to which team models worked best for parents.

Screening/Assessment

Informal observations during a screening activity led one evaluator to project that Alaska children in the 0 through 2 age group were slower in gross motor development compared to the national norm. Could Alaska's long dark winters play a role in this particular phase of child development? Test results are questionable for children living in the arctic, when test standardization was completed on

children living in a temperate climate. Alaska is planning to develop statewide norms of their unique population for the most frequently used developmental screening device. Communities in the far north can then better plan for programs that will enhance the development of young children.

A few Alaska communities are already recognizing the importance of toddler winter recreational programs. In one rural community the Infant Learning Teacher frequently visits these popular sessions, getting to know parents and sharing information about growth and development and the community's developmental screening program.

One aspect of P.L. 99-457 presented an overwhelming concern for rural communities. The new law requires services to be in effect 45 days after referral, but first a multidisciplinary evaluation must determine the child's and family's strengths and needs. Several years ago, Alaska developed three levels of evaluation services, making it possible for parents to access basic services in their own communities. Prior to this, all families from remote and rural communities were asked to travel to a regional evaluation clinic. A description of the levels of evaluation services follows.

A Level I Evaluation is conducted by two professionals who are either members of the community or visit the community frequently. Assessment is an ongoing process, and parents may opt for more information about their child in the subsequent assessments. A Level II evaluation requires that a team of therapists visit the village or rural community to conduct the assessment. The only time the family travels to a regional center is when the child needs a Level III comprehensive medical and developemental evaluation. The key here is to develop steps, beginning with basic services that are easily available and attainable in the family's community. The level of services are increased as indicated by the child's and family's needs and their readiness for services.

A much debated national question is, "Which model works best for evaluating infants and toddlers, the interdisciplinary or transdisciplinary team model?". In the interdisciplinary team model, communication among team members is well established. Information is shared among team members and sufficient time is allowed for collaboration. The transdisciplinary team model promotes teaching and learning among team members as they assume interchangeable roles and responsibilities. In Alaska professionals have discovered ways to involve families of infants and toddlers as full team members in both models. The key here is to develop flexible service delivery models that can be adapted and modified for each community.

Services

Families who live in rural and remote areas have chosen a life of simplicity, versatility, and independence. It is critical for early intervention programs to continue to foster these positive characteristics of self-sufficiency. Therefore, rural early interventionists must plan and provide programs based on teaching families how to care for their special need infants and toddlers in their own homes and communities versus the traditional professional intervention in a clinical setting. Strategies should assist rural families to develop confidence in planning for, and conducting, activities that enhance their children's development.

Technology is a critical aspect in getting services to rural and remote communities. Infant Learning providers video-tape children for further consultation or followup with specialized professionals. The teleconference can bring a team together for problem-solving of both client and program issues. The FAX has reduced the time between requesting authorization for services and the delivery of services.

Community health aides have been the primary health service providers in the villages for years. This model will be implemented in the future with the use of paraprofessionals in early intervention services. The key components here are training, supervision, and ongoing evaluation. Community providers are vital in informing the professional staff about value systems and interactional styles of the community and providing support to local families.

Staffing

Maintaining continuity of services with culturally competent clinicians for rural and remote regions will continue to challenge program administrators. Some staff incentives that are working include:

- A waiver plan which allows flexibility in hiring professionals who wish to work in rural remote regions. A training plan is then developed to assist the professional gain experience and/or education in deficient areas.

- A 10 percent salary increment after a professional has been an infant learning provider for three years.

- Recognition and service award for five or more years service.

- All expenses paid to travel for continuing education and inservice training twice a year. This includes part-time therapists who serve on the community-based evaluation team.

Collaboration

Listed below are some strategies that are working:

Parents, professionals and policy makers are coming together in a task force that connects private, local, state and federal programs. There is specific concern for the infant or child from a rural area who receives services from an urban medical center.

The state university has made the following advancements:

1. Courses are specific for rural early intervention providers.

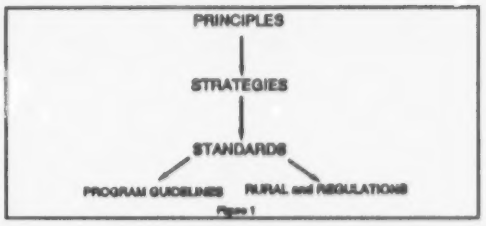
2. The media of telecommunications brings the classroom to the student in his/her own community. Professionals learn new skills and send video tape demonstrations back to their instructor.

Collabortive efforts are occurring among local, state, and federal agencies. A pediatrician from Indian Health Services (IHS), through a Memorandum of Agreement, is serving on a multidisciplinary evaluation team funded by the State of Alaska. The State of Alaska pays travel expenses and the IHS pediatrician evaluates infants and toddlers.

Policies and procedures that are not appropriate for rural service delivery are being challenged. Exciting new models show how services can be delivered more cost-effectively and with greater family satisfaction.

From Strategies to Policy

The concluding step in complying with P.L. 99-457 is the development of policy and procedures based on strategies that are working in rural communities and remote villages. Standards for each component of the law are being developed by a task force that is representative of parents and professionals in both rural and urban communities. Program guidelines with goals and objectives are also being written. The final step will be the revision of rules and regulations appropriate for all Alaska infants and toddlers regardless of their geographic location. (Figure 1)



Alaska will be ready for ALL infants and toddlers with special needs and their families...from the city, from the country, and from the villages in the bush.

The author wishes to acknowledge and thank all parents and professionals who contributed towards this team effort of planning for the compliance with P.L. 99-457 in the state of Alaska.

For more information contact Infant Learning Program, Support Services, 1231 Gambell Street, Anchorage, AK 99501-4627, (907) 277-1651.

References

Briggs, M.H. (1991). Team development: Decision-making for early intervention. Infant-Toddler Intervention: The Transdisciplinary Journal, 1, 1-9.

Mental Health Law Project. Will Early Intervention Programs Reach Families in All Communities?, 1101 15th St. NW, #1212, Washington, DC 20004.

FARM FAMILY REHABILITATION MANAGEMENT

Martha Wittkowski, Agency Director
Therese Willkomm, Director, Farm Family Rehabilitation Management (FaRM) Program
Chrystal Stanley, Assistant Director Farm Family Rehabilitation Management (FaRM) Program (Presenter)

Over 17,000 Iowa farm families are affected by severe physical disabilities including amputations, spinal cord injuries, back injuries and neuromuscular disorders. In addition, there are over 20,000 farm families affected by health-related conditions which limit their ability to complete essential farm and independent living tasks. Often, these disabilities prevent farm families from continuing a rural way of life.

Today, with technology and support services offered by the Easter Seal Farm Family Rehabilitation Management (FaRM) Program, someone who is severely disabled can remain active in a rural community. Farming is a way of life that values the family working together for a common goal. When one member is disabled, the entire family is affected. Psychological adjustment to disability can be extremely stressful for the entire family. The FaRM Program recognizes this and provides encouragement and support for the entire family. In addition, FaRM provides rural rehabilitation services to the family. These services promote a return to farming and the community, and increased independence through adaptive equipment, peer support services, and farm and home modifications.

Unfortunately, the delivery of rehabilitation technology services in rural areas can be very challenging due to isolation; lack of financial resources; attitudinal barriers among individuals who lack information on assistive technologies; and the distance one must travel to obtain needed services. To meet these challenges, the FaRM Program uses a community-based, consumer-responsive approach in providing assistive technology services. This approach maximizes involvement in local resources and encourages the consumer to actively participate in all phases of the service delivery process.

Because of the unique problems faced by farm families affected by physical disabilities, a Peer Technology Support Network has been established. This Network is composed of consumers who are currently using assistive technologies and are willing to share their experiences with newly disabled consumers. Seventy one consumers participate in the Peer Technology Support Network.

Another network, the Ingenuity Network, was established to aid in the service delivery process. This Network is composed of 68 Iowa volunteers with varied expertise in designing or fabricating assistive devices or modifications, obtaining materials, and locating commercially available devices.

In addition to these Networks, the FaRM Program has developed a Mobile Rural Assistive Technology Unit that can construct assistive technologies on site. The Unit is also used to promote statewide awareness of rural assistive technology and its impact on the independence of persons with disabilities. The Mobile Unit, and the Networks are essential in providing independent living services to rural farm families.

Some of the unique challenges faced by a consumer trying to live independently in a rural area include: mobility on rough rural terrain; making the farm home accessible using low cost solutions; and obtaining and maintaining personal care assistance.

In June of 1990 the FaRM Program held the first wheelchair rodeo featuring the most powerful outdoor electric wheelchairs on the market. Vendors demonstrated the chairs' abilities to enter a barn over a 2-inch high threshold; climb a 20 degree slope; maneuver through prairie grass; and cross an 18" deep mud hole with standing water. This event was attended by approximately 117 farm families

from 15 states. In conjunction with this rodeo, a conference was held on Progress in Farming with a Physical Disability. Seminar discussions included: adaptive farm equipment, machinery, and buildings for farmers with physical disabilities; recreational adaptations; alternative agriculture ventures; and farm home accessibility.

Therese Willkomm, the director of the FaRM Program, has produced a manual on hiring and managing a personal care assistant in a rural area. This manual includes ideas on recruiting, interviewing, and hiring an attendant and establishing hours, wages, performance guidelines, and performance reviews. The Peer Support Network also advises on personal care assistant management.

The FaRM Program receives its funding from a variety of sources including agricultural related businesses and rural-based organizations such as John Deere, Land 'o Lakes, the Farm Bureau, Successful Farming, Iowa Pork Producers, St. Luke's Foundation, Casey's General Stores, and the Dole Foundation.

In addition, special subcontract project grants have been awarded to the FaRM Program from Purdue University's Breaking New Ground Project; The University of Iowa's Program for Assistive Technology; and the University of Iowa's Agricultural Medicine Program. The FaRM Program has also received funding from the Rehabilitation Services Administration and a research grant from the National Easter Seal Society.

Since the FaRM Program began in 1986, it has served over 360 Iowa farm families affected by physical disabilities. Each year the program serves approximately 110 clients and responds to over 400 technical assistance requests from all 52 states and 7 countries. During the last year, over a quarter of a million dollars worth of assistive technologies were provided to Iowa farm families through the Ingenuity Network and Mobile Unit. These technologies were provided through donated labor, materials, and technologies.

Because of its unique features and success, the FaRM Program has been chosen by the National Easter Seal Society to receive its Excellence in Program Innovating Award. The program has been replicated in Wisconsin and Minnesota. In addition, an amendment, initiated by the National Easter Seal Society and the FaRM Program, was added to the 1990 United States Department of Agriculture "Farm Bill" to aid in establishing additional FaRM Programs throughout the United States.

FaRM is a unique program that provides free, on-site rural rehabilitation services to farm families affected by physical disabilities. The program's consumer responsive approach has made it a forerunner in the rural rehabilitation field.

For more information contact Easter Seal Society of Iowa, Inc., P.O. Box 4002, Des Moines, IA 50333, (515) 289-1933.

Innovative Rural Interpretations of Disability Laws and Practices

THE COMMON THREADS

♦ "You can do things the right way or you can do the right thing." You may need to review policies to see if the goal is success for the consumer. **If rules and regulations don't work, change them.** Grass roots efforts work best. Register voters and get out the vote. Hold legislative workshops; attend city council meetings. Write legislation in clear, concise language. Identify nurturing and supportive leaders. Use consumerism to its best advantage.

♦ Be optimistic. Learn the rules well, be proficient in using them, then learn to work around them when it meets consumers' needs. Professionals are sometimes prey to "statute-driven vulnerability"--responsibility for enforcing unpopular rules and regulations. Be pragmatic, consumer-driven and sensitive. Make standards consistent. Programs and program administrators may be a consumer's best advocates. Before talking to policymakers, identify your assumptions about laws and discover any hidden agendas members of your group may harbor.

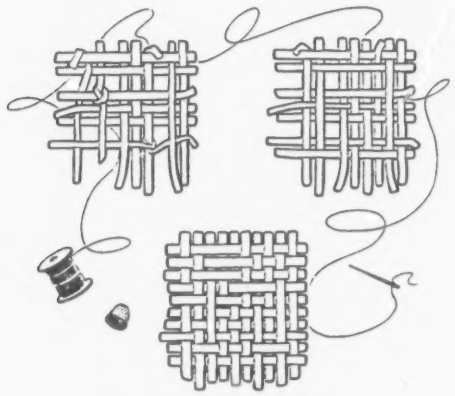
♦ View the Americans with Disabilities Act as an opportunity to increase community awareness. Sponsor public school disability awareness programs. Educate everyone: consumers, providers, officials, the general public. Accentuate the positive; introduce individuals and their individual needs rather than stressing compliance with requirements. Support universal accessibility. Use agencies, such as the Architectural Transportation Barriers Compliance Board and Easter Seal Society, as resources to interpret ADA requirements. Centralize information about the ADA. Use state housing and finance agency resources (see the presentations under "Support Systems" for a description of how Rhode Island did this).

♦ Pilot projects can be designed to legitimately work outside existing rules. See what other states are doing and decide if your state could replicate promising projects. It is possible to do unusual programs or arrangements without violating the rules. Demonstration projects have advantages and disadvantages. Disadvantages: they're short-term and people are sometimes reluctant to be involved in temporary activities; three-year timelines create difficulties--five-year projects would work better; grants and projects are task-specific--long-range planning and staffing are difficult; there should be more grants for administration activities and for research on community needs; although we learn as much from failure as from success, grant projects jeopardize their funding if they don't meet their initial objectives--results and final reports are sometimes manipulated to create the illusion of success. Advantages: many demonstration and pilot projects allow funds to be used for training; if projects are successful, the funding is usually renewed; projects are necessary for community-based research and development, program planning, experimentation, and evaluation; projects allow providers to compete, although rebuilding the coalition after the competition ends is crucial.

♦ Stretch your resources; the same eligibility requirements could be instituted for several programs, so consumers qualify for more cross services. Use the same dollar several different ways. **Be creative and positive;** show how money invested in a program really helps an individual.

♦ Remember: "Ignorance is bliss," and "It's easier to get forgiveness than permission."

Small Group Facilitators: Mike Jakupcak, Kathleen Miller Green, Kathy Jackson, Shawn Clouse (Rural Institute on Disabilities).



CONCLUSION

Conclusion

THE MOST COMMON THREADS

The following are statements that were reiterated in Common Threads sessions throughout the conference. While this doesn't qualify them as Eternal Rural Truths, they do distill the experience of many rural people, from many different places and situations:

♦ Unique rural programs often don't realize that they are doing something extraordinary. Other programs may think they're doing something unique, when actually they're re-inventing the wheel. There may be inadequate contact with the "outside world" of disability services due to lack of funds, time, and networking expertise; a national clearinghouse could improve communication.

♦ Consumers are the most important element in the rural disability equation. Delivering services to consumers is the impetus for much of the creativity rampant in rural programs: the formal and informal interagency collaborations, the innovative service delivery techniques and training methods, the funding plans that stretch scarce dollars and make them do double (or triple) duty.

♦ Consumers need to be educated on the Americans with Disabilities Act, on how to ask questions of professionals, on raising their expectations of finding solutions to minor inconveniences and major problems. Consumers also need to be educators, working to increase public awareness, sharing their experiences, providing peer support services for others, and informing service providers of training and accessibility needs and preferred service delivery methods. They need to be active participants in the habilitation/rehabilitation process.

♦ Service providers need to solicit consumer input and use consumers' expertise to personalize training and to solve accessibility problems. The provider needs to be sensitive to the consumer's cultural background, attitudes, language, vocabulary, and level of comprehension. The service provider must be a consumer advocate personally, publicly and politically. Consumers and providers must work together to develop consumer networks and consumer/provider/business coalitions.

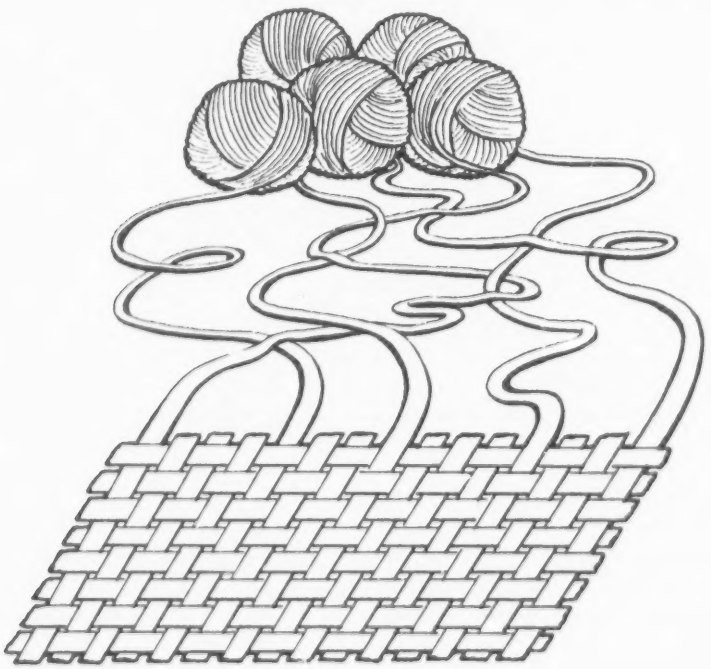
♦ Disability programs must become an integral part of the rural community, both contributing to the community and sharing its resources. Service providers need to be familiar with local systems and procedures, and must adapt the program to serve local needs. Natural support systems exist in rural areas--the wise service provider will become adept at recognizing and organizing them. Consumers and service providers must participate in cultural and social events, join social organizations, patronize local businesses, entertain and educate community members, hire local employees, and recruit volunteers from all walks of life. The local media are crucial to maintaining visibility for

programs and issues. Every school, library, church, hospital, business, club or organization, every branch of government is a potential resource. Every community member has some expertise or quality that could enrich a program.

♦ The **Americans with Disabilities Act** is an opportunity for service providers to consult with businesses and local governments on disability issues. Consumers and service providers can enlist the cooperation of key decision-makers in the community by stressing that compliance with ADA guidelines will have a positive economic effect, by showing how specific individuals with disabilities will benefit, and by rewarding and promoting barrier-free businesses and agencies. Rural people must be vocal and visible, to ensure that they receive equal benefits from the Act.

♦ **Technology** is particularly important in rural areas where transportation and roads may be inadequate, the weather uncertain, and distances great. Telephones and computers provide access to information and ease long-distance networking and conferencing. Many agencies and organizations provide information on toll-free lines. Public radio and television can educate the community on disability issues. Public access television can also be used to train consumers, and can provide equipment and technical expertise to create training videotapes for staff and consumers. Video technology is common even in the most remote areas and videotapes can supplement training and evaluation over great distances. Computers and telecommunication devices for the deaf allow those with communication disabilities access to other people. Technology can link consumers, service providers, the community, and the world.

♦ Rural service providers need to be: **Creative, Flexible, Credible, and Knowledgeable.**



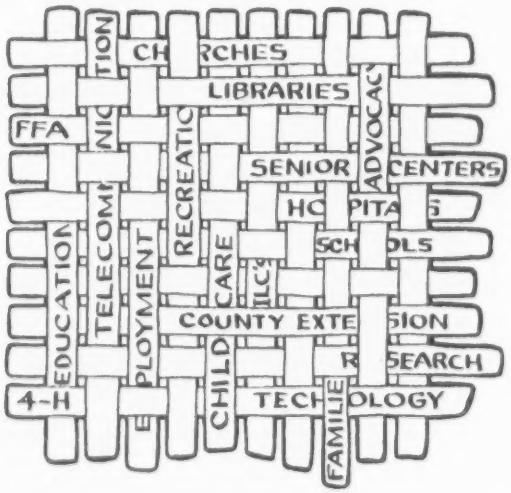
RURAL DISABILITY SERVICES NETWORK

RURAL DISABILITY SERVICES NETWORK

Finding rural disability services is often a challenge for consumers and providers alike. Some of the best rural programs are not part of any disability information network, are not part of the publishing circuit, and may not get disability publications or newletters. These programs have had no incentive to document their work for a national audience. In an effort to locate these rural resources, the Rural Institute on Disability is collecting information about programs that serve people with disabilities in rural areas.

The following is an initial directory of rural programs being compiled by the Rural Institute. Included are programs from around the country, many of whom participated in the Common Threads conference. The Rural Institute will publish a more complete directory at a later date.

Included at the end of the Network section is a **Rural Disability Services Network Worksheet**. If you know of a program which should be part of this network, please copy the worksheet, complete the information, and forward it to the Montana University Affiliated Rural Institute on Disabilities, 52 Corbin, The University of Montana, Missoula, MT 59812; or call (406) 243-5467 to speak with a staff person directly or (800) 732-0323 to leave a message and we'll get back to you.



ALASKA

Access Alaska, Inc.
3550 Airport Way #3
Fairbanks, AK 990709

Phone: 907-479-7940
FAX:
TDD: 907-479-7940

Contact: Bill Crandall, HAMMER Project Coordinator

Services: Services for individuals with severe disabilities, traumatic brain injuries, and visual impairment are provided. IL skills training, housing referral and modifications, and a recreation program are also offered.

Eligibility: No restrictions except the MHDD, Rural Villages, and Native Populations grants which have specific guidelines.

Referral: Referrals are open.

"The best feature of this program is...:

General Comments: Access Alaska identifies its clients through referral and personal contact. The program utilizes the state vocational rehabilitation division, hospitals, OTs, PTs, families and other agencies as resources. Access Alaska serves a population of fewer than 50,000 in the interior bush communities which are normally not accessible by roads.

Infant Learning Program
Maternal, Child & Family Health
Department of Health & Social Services
1231 Gambell Street
Anchorage, AK 99501

Phone: 907-277-1651
FAX:
TDD:

Contact: Thelma Robinson, Pediatric Nurse Specialist

Services: The Infant Learning Program offers comprehensive, multi-disciplinary early intervention services.

Eligibility:

Referral:

"The best feature of this program is...bringing an old program into compliance with PL 99-457."

General Comments:

Kodiak Area Native Association (KANA)

Vocational Rehabilitation
402 Center Avenue
Kodiak, AK 99615

Phone: 907-486-5725
FAX: 907-486-2763
TDD:

Contact: Joe Kelley, Project Director

Services:

Eligibility: To be eligible for KANA services the consumer must: have a physical or mental disability; be handicapped to employment; be Native American; and/or have reasonable expectation that they can be employed.

Referral: Native Americans are encouraged to apply.

"The best feature of this program is...the flexibility of the KANA program to meet the individual needs of the people it serves."

General Comments: The KANA project uses medical, physical, psychological and vocational assessments to identify its consumers. They use physicians, mental health workers, PTs, OTs, and VR counselors as resources. "Rural" may mean an outlying area on the road system around Kodiak City or it may mean a Kodiak village accessible only by air.

Sitka PACS: Center for Community

PO Box 6069, 201 Katlian, Suite 104
Sitka, AK 99835

Phone: 907-747-6960
FAX: 907-747-4868
TDD: 907-747-6960

Contact: Margaret Andrews, Rural Services Coordinator

Services: The Center for Community offers independent living, community access, vocational, infant learning, functional skills for youth in schools, respite, assistive technology, parent support, and a community resource network.

Eligibility: The consumer must meet Alaska's state guidelines for developmental disability.

Referral:

"The best feature of this program is...its individualized service that is parent and/or focus person driven."

General Comments: We are looking for the outcomes each client or family indicates THEY want. "Rural" means the four villages outside Sitka that must be accessed by ferry or floatplane.

ALABAMA

Stateside Independent Living Program

3421 5th Avenue South
Birmingham AL 35222

Phone: 205-251-2223
FAX:
TDD:

Contact: Rhonda Stark, Lead Specialist

Services:

Eligibility: Eligibility is determined by Alabama's Vocational Rehabilitation Homebound Program or the regular VR program.

Referral:

"The best feature of this program is...our frequent contact with clients and our peer support services."

General Comments: "Rural" means being isolated from agencies and services (especially transportation). Resources are extremely limited and many of our rural counties are impoverished. Social interactions and skills are poor.

ARIZONA

Independent Living Project

Office of Special Education and Rehabilitation Programs
PO Box 1420
Window Rock, AZ 86515

Phone: 602-871-7491
FAX: 602-871-7474
TDD: 602-871-5076

Contact: Donna J. Chacho, ILP Coordinator

Services: The Independent Living Project provides IL skills training, self-care, transportation, referrals and coordination, rehabilitation engineering consultant evaluation, and psychological and vocational evaluations on a contractual basis.

Eligibility: The consumer must be severely disabled.

Referral: Clients are accepted as walk-ins or are referred from other programs such as hospitals, community health programs, schools, the Social Service Administration, parents and family members.

"The best feature of this program is...being persistent in helping clients break through barriers, to overcome. Instilling in their minds the desire to get involved, to take charge of their lives."

General Comments: Outcomes would be to work with the client to identify problems and ways to overcome the problems.

IOWA

Farm Family Rehabilitation Management
Easter Seal Society of Iowa, Inc.
PO Box 4002
Des Moines, IA 50310

Phone: 515-289-1933
FAX:
TDD:

Contact: Chrystal Stanley, Assistant Director

Services: The FaRM Program provides agricultural worksite modification, peer support, independent living, health care coordination, and vocational rehabilitation.

Eligibility: The consumer must have a physical disability and live or work on a farm.

Referral: Anyone may refer a consumer by calling or writing.

"The best feature of this program is...we are consumer responsive and provide on-site direct service, free of charge."

General Comments:

KANSAS

LINK, Inc.
PO Box 1016, 1310 Walnut
Hays, KS 67601

Phone: 913-625-2521
FAX:
TDD: 913-625-2521

Contact: Brian Atwell, Coordinator

Services: LINK, Inc. offers information and referral, independent living skills training, advocacy, peer counseling, deaf services, housing, personal care attendant services, a recreation program, transportation, and ADA technical assistance.

Eligibility: Any adult with a disability is eligible for LINK, Inc. services. Some teens who are not served by the school system may be eligible.

Referral: The consumer may request services and interagency referrals are accepted.

"The best feature of this program is...that it's consumer-driven and rural-based."

General Comments: Individuals' needs are assessed through evaluation; LINK, Inc. then uses any available resource to meet the needs of their consumers.

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LOUISIANA

New Horizons
4030 Wallace Avenue
Shreveport, LA 71108

Phone: 318-635-3652
FAX:
TDD:

Contact: Ruth McHalffey, Services Director

Services: New Horizons offers independent living, peer counseling, pre-employment skills training, independent living skills training, leadership training, minority outreach, and adapted aquatics.

Eligibility: Any adult with a disability who is capable of living independently is eligible for New Horizons' services.

Referral: Consumers have direct access to New Horizons.

"The best feature of this program is...that it's consumer-controlled. The consumer sets his/her own goals and determines when those goals have been met."

General Comments: Case managers conduct an intake interview using the agency's IL skills assessment instrument. Goals are then set. The consumer is placed in a group or individual living situation or referred to a more appropriate facility.

MARYLAND

Calvert Association
for Citizens with Mental Retardation, Inc.
PO Box 1860
Prince Frederick, MD 20678

Phone: 301-535-2413
FAX: 301-535-1314
TDD:

Contact: Kate Rollason, Executive Director

Services: The Calvert Association provides group homes, vocational and supportive employment, family and individual support, respite services, transportation, and referral.

Eligibility: All children with any disability and adults with mental retardation in Calvert County, MD, are eligible.

Referral: The Association accepts all applications which meet eligibility criteria.

"The best feature of this program is...an integrated day care, a nationally recognized respite and family support program, a consumer-centered approach to residential, vocational, supportive employment, and family and individual approaches."

General Comments: The Calvert Association provides real homes, real friends, and real jobs for people with mental retardation. We will open a group home for children in November, 1991.

MICHIGAN

Vintage Program and Independent Living Program
Michigan Commission for the Blind
411-G East Genesee
Saginaw, MI 48607

Phone: 517-771-1765
FAX:
TDD:

Contact: Dr. John E. Crews, Independent Living Supervisor

Services: The program provides services for individuals with hearing impairment, physical, mental and emotional impairments.

Eligibility: The consumer must be legally blind and/or medically certified.

Referral: The Commission refers to other agencies.

"The best feature of this program is...the direct services between client and rehabilitation teacher."

General Comments: The agency uses home screening, hearing and vision clinics, and self referral to identify consumers. The intention is to improve the clients' daily living skills; helping them to remain independent and living in their own homes. "Rural" means great distances between the client and home base.

MINNESOTA

Functional Industries
The Wright Connection and the Seniors' Program
Box 336
Buffalo, MN 55313

Phone: 612-682-2910
FAX: 612-338-3097
TDD:

Contact: Barb Tevogt, Coordinator

Services: Functional Industries offers a supported retirement day program, retirement skills training for seniors with developmental disabilities, a training and habilitation program with vocational emphasis for younger adults, and transportation.

Eligibility: Functional Industries requires that the consumer be 21 years of age and classified as having mental retardation before the age of 21 to qualify for services.

Referral: Human services agencies, schools and residential facilities may make referrals to Functional Industries.

"The best feature of this program is...versatility. We deal with all needs of each individual, not just vocational."

General Comments:

Options Interstate
Resource Center for Independent Living
318 3rd Street, NW
East Grand Forks, MN 56721

Phone: 218-773-6100
FAX: 218-773-7119
TDD: 218-773-6100

Contact: Randy Sorensen, Operations Manager

Services: Options Interstate offers information and referral for services and housing, a resource center, attendant care training and registry, supervisory nurse training and registry, peer support, service coordination, and independent living skills training. Transition from school to community living services, outreach presentations, self-advocacy training, systems advocacy, recreation services, and recreation I & R for federal and state agencies are also offered. A computer is available for adaptive equipment.

Eligibility: Options Interstate Resource CIL uses the federal definition of disability: severe mental or physical disability with a reasonable expectation that IL services will be of benefit. The Center does not refuse services.

Referral: Referrals may be made by people in the community, other agencies, or by walk-ins.

"The best feature of this program is...our open door policy. Anyone can come in with any problem or disability and our staff will let the paperwork go and try to help that person."

General Comments: The program covers 15,000 square miles in Minnesota and North Dakota and has existed for five years. It provides technical assistance to other beginning programs. Options Interstate Resource Center sponsors an annual summer "End-Dependence Day" celebration, with accessible fishing and other water activities, Native American activities, games and prizes.

MISSOURI

Services for Independent Living
1301 Vandiever Drive, Suite Q
Columbia, MO 65202

Phone: 314-874-1646
FAX:
TDD: 314-874-4121

Contact: Brain Dale, Rural Independent Living Specialist or Steve Banister, Program Director

Services: Services for Independent Living offers independent living skills, assessment, personal care assistant training, PCA management training, head injury support services, accessibility assessment, transportation, rights and benefits counseling, and peer support.

Eligibility: Services for Independent Living has no eligibility requirements or restrictions.

Referral: Consumers may call, write, or walk-in.

"The best feature of this program is...that the staff are willing to work with the consumer, not for the consumer."

General Comments: The agency is consumer-directed and involved in coalitions and legislative advocacy.

Southwest Center for Independent Living (SCIL)
1856 East Cinderella, Suite E
Springfield, MO 65804

Phone: 417-886-1188
FAX:
TDD: 417-886-1188

Contact: Ann Morris, Executive Director

Services: The Southwest Center for Independent Living offers independent living skills, advocacy, peer support, a personal care attendant program, and support groups for individuals with spinal cord injury, post-polio conditions, and hearing impairment. It also offers a resource library, an information and referral program, and voter registration. In addition, the Center conducts accessibility surveys and publishes a bimonthly newsletter.

Eligibility: All persons in Southwest Missouri with any disability who are 16 years or older, are eligible to receive services from SCIL. In addition, community services are provided to the general public.

Referral: Referral policy is open.

"The best feature of this program is...consumer control makes the difference."

General Comments: Independent living is based on the concept that people with disabilities know their needs best and have the right to make decisions regarding their daily lives. Consumer control means management by people with disabilities. At SCIL, the majority of both the board of directors and the staff are people who have disabilities. It also means that the people who receive our services decide which services they want and set their own goals for increased independence. The independent living process at SCIL is one of teamwork. Advisory Councils composed of people with disabilities are one way that SCIL keeps informed of the ongoing needs and issues vital to our work toward achieving a barrier-free society.

MONTANA

Blaine County Activities, Inc.
PO Box 457
Harlem, MT 59526

Phone: 406-353-2611
FAX:
TDD:

Contact: Dan Richman, Executive Director

Services: Services for individuals with developmental disabilities.

Eligibility: The consumer must have a developmental disability.

Referral: Statewide waiting list.

"The best feature of this program is...placement of individuals with developmental disabilities into the job market."

General Comments: Blaine County Activities uses a screening process to identify and assess individuals. The program trains individuals on normalization and main-streaming into society. "Rural" means being long distances from specialists and medical services.

North Central Independent Living Services

104 2nd Street South
Great Falls, MT 59405

Phone: 406-452-9834
FAX:
TDD: 406-452-9843

Contact: Tom Osborn, Executive Director

Services: The North Central Independent Living Services provides case management, peer counseling, information and referral, and independent living skills training.

Eligibility: The consumer must have a disability to be eligible for North Central Independent Living Services.

Referral: Referrals may be personal or through the aging services network.

"The best feature of this program is...:

General Comments:

Occupational Therapy Associates of Bozeman, Livingston, Butte, and Great Falls

300 North Willow, Suite 2003
Bozeman, MT 59715

Phone: 406-586-3716
FAX:
TDD:

Contact: Linda Botten, OTR/L, President

Services: Occupational therapy in all service delivery areas.

Eligibility:

Referral: Referrals for Occupational Therapy Associates services must be made by a physician.

"The best feature of this program is...meeting specific consumer needs, having flexibility, and working on a contractual base."

General Comments: Occupational Therapy Associates is increasing outreach to rural communities.

SUMMIT Independent Living Center, Inc.

1280 South 3rd West
Missoula, MT 59801

Phone: 800-843-9655
FAX:
TDD: 406-728-1630

Contact: Michael Regnier, Advocacy Coordinator/IL Specialist

Services: SUMMIT offers independent living skills education and training, attendant management training, peer counseling, family counseling and education, personal and systems advocacy, support groups, recreation, transitional services, an equipment rental program, a telephone relay and interpreter services, a resource library, personal care attendant training and referral, disability awareness and sensitivity training, consultation, and volunteer services.

Eligibility: People with mobility impairments, neurological disorders, hearing impairments, learning disabilities, visual impairments, and other disabling conditions are eligible for SUMMIT's services.

Referral: SUMMIT accepts referrals from health care professionals, other agencies, and consumers.

"The best feature of this program is...the newly emerging advocacy program."

General Comments: A needs assessment tool developed by SUMMIT staff is used to identify/assess consumers. Any available resources, such as grants, state funding, and referral to other sources, are used. "Rural" defines most of SUMMIT's seven county service area.

Vocational Rehabilitation Services (Bozeman)

Montana Department of Social & Rehabilitation Services
202 South Black
Bozeman, MT 59715

Phone: 406-587-0601
FAX:
TDD:

Contact: Susan Miller, Vocational Rehabilitation Counselor

Services:

Eligibility: To qualify for Vocational Rehabilitation services in Montana, a consumer must have a vocational disability and have a reasonable expectation for employment.

Referral: Referral may come from any source.

"The best feature of this program is...that we help people get back to work."

General Comments: Montana Vocational Rehabilitation uses vocational, psychological, and physical evaluations to identify and assess potential consumers.

Vocational Rehabilitation Services (Kalispell)

Montana Department of Social & Rehabilitation Services
PO Box 2357
Kalispell, MT 59903-2357

Phone: 406-755-5408
FAX:
TDD:

Contact: Carl Newton, Vocational Rehabilitation Counselor

Services: Vocational rehabilitation services including training and related diagnostic services.

Eligibility: Consumer must meet state requirements for eligibility.

Referral: Applicants may be referred by anybody or themselves.

"The best feature of this program is...is that we provide services."

General Comments: The State of Montana has three criteria to identify/assess consumers: 1. a diagnosable disability; 2. a vocational handicap; and 3. reasonable expectation of employment. The agency uses any resource that is available. Montana's Vocational Rehabilitation Services' mission is to find successful, compatible employment for consumers.

Vocational Rehabilitation Services (Northern Cheyenne)

Morningstar Opportunities
Resources & Employment (MORE) Workcrew
Box 67
Lame Deer, MT 59043

Phone: 406-477-6722
FAX:
TDD:

Contact: Claude Dodson, Director

Services: The Northern Cheyenne Vocational Rehabilitation Services offers vocational rehabilitation services and a rehabilitation facility.

Eligibility: The Northern Cheyenne Vocational Rehabilitation Services follows federal regulations for vocational rehabilitation: The consumer must have a physical or mental disability; the disability must be a barrier to employment; and there must be reasonable expectation that the services will help the client to become employed.

Referral: Referrals must be made in writing and include a signed release to permit the agency to provide services.

"The best feature of this program is...employment outreach."

General Comments:

Yellowstone Valley Center for Independent Living, Inc.

3304 2nd Avenue North
Billings, MT 59101

Phone: 406-259-5181
FAX:
TDD: 406-259-5181

Contact: Rena Metcalf, Independent Living Coordinator

Services: Information and referral, guidance and counseling, emotional support, advocacy and direct assistance are services offered by Yellowstone CIL.

Eligibility: Medical documentation of a severe disabling condition is required by Yellowstone CIL for services.

Referral:

"The best feature of this program is...:

General Comments: "Rural" is eastern Montana - it is sparsely populated and tends to be very conservative. A lot of innovative approaches must be taken.

Montana University Affiliated Rural Institute on Disabilities

The University of Montana
52 Corbin Hall
Missoula, MT 59812

Phone: 406-243-5467
FAX: 406-243-2349
TDD: 406-243-5467

Contact: Diana Spas, Information and Dissemination Specialist and Kathy Dwyer, Information and Dissemination Specialist

Services: The Rural Institute conducts research and training activities with health, education and welfare agencies, as well as private organizations that focus on rural needs. It provides technical assistance to organizations and agencies in rural areas. The Rural Institute also collects, coordinates, and disseminates information related to rural disability issues.

Eligibility: Anyone interested in rural disability issues may contact the Rural Institute.

Referral: Anyone interested in rural disability issues may contact the Rural Institute.

"The best feature of this program is...its effort to improve the well-being, self-sufficiency, and productivity of Americans with disabilities who live in rural areas."

General Comments: The Rural Institute conducts service, training, technical assistance, research and information dissemination activities which help people with disabilities in rural areas find quality social and educational services and health care. Increasing the quantity and quality of disability services professionals and care providers in rural settings is major goal of the Institute; as well as developing state-of-the-art approaches to meet the challenges of living with a disability in a rural area. The Rural Institute also provides information about rural issues to the public and professionals.

NORTH CAROLINA

Family Caregiver Project

University of North Carolina at Charlotte
Psychology, UNCC
Charlotte, NC 28223

Phone: 704-547-4741
FAX:
TDD:

Contact: C.D. Fernald, Co-Director

Services: The Family Caregiver Project provides research and development, training, curriculum and training development.

Eligibility:

Referral:

"The best feature of this program is...helping families caring for different disabilities to come together to learn from and support each other."

General Comments: The Family Caregiver Project publishes training manuals ("The Caring Families" Manual) to provide information and support for families caring for relatives with developmental disabilities, mental illness or impairments of aging. We also have a "Leader's Manual" for families or professionals leading education and support groups.

NORTH DAKOTA

Vocational Rehabilitation

State of North Dakota
400 22nd Avenue, NW
Minot, ND 58701

Phone: 701-857-0882
FAX:
TDD:

Contact: Steve Dornburg, Vocational Rehabilitation Counselor

Services: Vocational rehabilitation services and independent living programs are offered by the North Dakota Office of Vocational Rehabilitation.

Eligibility: Federal criteria determine eligibility.

Referral: Referral is made for anyone requesting services; individuals with severe disabilities are given priority status.

"The best feature of this program is...

General Comments: The North Dakota Office of Vocational Rehabilitation serves Minot, a city of approximately 30,000 residents. It also provides services to many small towns of less than 3,000 people plus large areas of farms and ranches.

NEW MEXICO

Las Cumbres Learning Services

Box 1362
Espanola, NM 87532

Phone: 505-753-4123
FAX:
TDD:

Contact: Donna Sanchez, Intake Coordinator and Maribeth Culpepper, Respite Director

Services: Las Cumbres provides an array of services including respite care, behavior management, nutritional assessment and counseling, and public awareness education, transition from early childhood to public school, early childhood screening clinics, an integrated preschool and a for-profit integrated daycare, vocational assessment, orthopedic clinics, physical therapy. Las Cumbres' supported employment program uses enclaves, a benchwork model, and mobile crews. A group home and community- and home-based supported living are also features.

Eligibility: Eligibility requirements vary with each program. The childrens' programs require that the individual be at risk for developmental disability, mental delay or be developmentally delayed according to federal definition. Adults must be developmentally disabled. To qualify for therapy, consumers must be eligible for state funding, private insurance coverage, or be covered by their school district.

Referral: Referrals for most child and adult services may come directly from doctors, schools, early childhood screening clinics, or the individual. A doctor's referral is required for therapy.

"The best feature of this program is...its ability to meet the unique needs of individuals in a tri-cultural, very economically-diverse area, and to retain its qualified staff."

General Comments: The agency offers 1-3 year stipends for bilingual staff (English and Spanish/sign language/Native American) and offers college stipends to local residents in return for employment with the agency. The therapists are bilingual.

OKLAHOMA

Progressive Independence

121 North Porter
Norman, OK 73071

Phone: 405-321-3203
FAX:
TDD: 405-321-2942

Contact: Candace Low, Executive Director

Services: Progressive Independence offers independent living skills training, peer counseling, and personal assistance training and referral. They also provide accessibility assessments and modifications, employment training and placement and family and consumer support groups. The

agency also offers services to people with hearing impairments, an equipment loan program plus social and recreational programs.

Eligibility: Progressive Independence provides services to all citizens with disabilities and their families.

Referral: Progressive Independence accepts all referrals and if they are unable to provide needed services, they will refer to a more appropriate agency.

"The best feature of this program is...the quality and comprehensiveness of the service, the community support, and the commitment of the staff toward improving the quality of life for all citizens."

General Comments: Progressive Independence serves 30,000 people through awareness education.

Oklahoma Independent Living Resource Center

321 South 3rd, Suite 2
McAlester, OK 74501

Phone: 918-426-6220
FAX: 918-426-6222
TDD: 918-426-6220

Contact: Don Walker, Community Services Coordinator

Services: Transportation, peer counseling, group sessions, and employment are among the independent living services offered by the Oklahoma Independent Living Resource Center.

Eligibility: Disability is the only criteria for eligibility.

Referral:

"The best feature of this program is...our public forums identified social/recreation as the prime need. We excel in providing these services."

General Comments: McAlester, in Pittsburgh County, is located in rural SE Oklahoma. The Oklahoma Independent Living Resource Center accepts consumers based on their claim of disability. The Center conducts intake interviews with consumers receiving services.

OREGON

Technology Access for Life Needs (TALN)

Region I, Blue Mountain Community College
Box 100
Pendleton, OR 97801

Phone: 503-276-1260
FAX: 503-276-6119
TDD: 503-276-1260

Contact: Amy Spiegel, Region I TALN Coordinator

Services: Assistive technology lending library, assessment, funding demonstrations, regional needs assessment, EDNET (interactive TV), recreation, and assistive technology are among the services offered by TALN.

Eligibility: Assistive technology is unavailable outside of the state of Oregon.

Referral: TALN offers direct access to their services.

"The best feature of this program is...that it has no eligibility requirements, serves people with any disability, of any age, and provides all technologies."

General Comments:

UTAH

Easter Seal Society of Utah, Inc.
331 South Rio Grand, #206
Salt Lake City, UT 84101

Phone: 801-531-0522
FAX: 801-531-0575
TDD: 801-531-9372

Contact: John Pinter, President

Services: The Easter Seal Society of Utah provides job placement, respite/family support, assistive technology, support groups and legislative advocacy.

Eligibility: Eligibility requirements vary.

Referral:

"The best feature of this program is...that our mission allows us to work with a variety of disabilities and age groups."

General Comments:

WASHINGTON

Vocational Rehabilitation Part A - IL Program
Washington Department of Social and Human Services
4101 Meridian
Bellingham, WA 98227

Phone: 206-676-2021
FAX:
TDD: 206-676-2021

Contact: Joyce Tighe, Independent Living Counselor

Services:

Eligibility: To be eligible for Vocational Rehabilitation services, the consumer must have a disability and no other service provider.

Referral: Referrals for Vocational Rehabilitation's services may come from other agencies, other consumers, or the individual.

"The best feature of this program is...that it serves people that 'fall through the cracks' and tries to overcome barriers to the participant's family and community life."

General Comments: The agency identifies consumers by outreach to rural areas and uses an IL assessment tool. "Rural" is any community outside of Seattle's King County.

WISCONSIN

Center for Independent Living
University of Wisconsin-Stout
Menomonie, WI 54751

Phone: 715-232-2150
FAX:
TDD:

Contact: Sue Hebert, Resource Counselor

Services: Center for Independent Living, University of Wisconsin-Stout provides accessibility, peer advisement, advocacy, technical assistance, and disability awareness.

Eligibility: The consumer must reside within our eleven-county area, be 16 years old or older and have a disability to be eligible.

Referral: The referral policy is open; consumers may be referred by a social worker, family, friend, or themselves.

"The best feature of this program is...flexibility, room for creative ideas."

General Comments: Assessment is an ongoing process -- open-ended -- as new goals/concerns arise. Resources can be as unique as the consumer's goals. "Rural" means lots of "on the road" time for resource counselors whose budgets must allow for travel expenses. It also reflects the challenge of consumer involvement -- consumers are not able to come together for center activities and to meet other consumers.

Easter Seal Society of Wisconsin, Inc.
Northern Office
115 East Polk Avenue
Eau Claire, WI 54701

Phone: 715-834-0460
FAX:
TDD:

Contact: Joan M. Johnson, Regional Representative

Services: The Easter Seal Society of Wisconsin, Northern Office, provides accessibility assistance, equipment loan, funding and the Rural Center for Farmers with Disabilities.
Eligibility:

Referral: Referrals to the Easter Seal Society of Wisconsin can be made by the consumer, health providers, family, or friends.

"The best feature of this program is...all disabilities are included."

General Comments:

WEST VIRGINIA

University Affiliated Center for Developmental Disabilities
West Virginia University
918 Chestnut Ridge Road, Suite 2
Morgantown, WV 26505

Phone: 304-293-4692
FAX: 304-293-7294
TDD:

Contact: Don Kincaid, Deputy Director

Services: The Center provides comprehensive services.

Eligibility: The Center has no eligibility requirements or restrictions.

Referral: The Center's referral policy is based on personal contact with consumers.

"The best feature of this program is...the broad range of technical assistance, consultation, and services provided throughout West Virginia."

General Comments:

VERMONT

Rural & Farm Family Vocational Rehabilitation Program
University of Vermont Extension System
Morrill Hall
Burlington, VT 05405

Phone: 802-656-3013
FAX:
TDD:

Contact: Daryl Lowry, Program Supervisor

Services: Physical restoration, assistive technology, vocational evaluation, counseling, financial management, vocational training and placement, and worksite modifications are the services provided.

Eligibility: Eligibility is based on the presence of a physical or mental disability which is a substantial handicap to employment, and a reasonable expectation that services will benefit the consumer in terms of employment.

Referral:

"The best feature of this program is...[most of the] staff come from an agricultural background so they relate well with the clientele."

General Comments: Our clients mainly come from referral sources or self referred. We use all other programs and agencies as they are appropriate. Outcomes are successful rehabilitations. "Rural" means living and earning an income in rural settings. Rural also means living in the country in a quiet setting -- being away from all the resources and advantages of a town or city.

RURAL DISABILITY SERVICES NETWORK WORKSHEET

AGENCY NAME:_____

Mailing Address:_____
STREET CITY COUNTY STATE ZIP

Street Address, if different from above_____

Phone: _____ FAX:_____ TDD: _____

Contact Person:_____ Title:_____

TYPE OF AGENCY (check all that apply):

___Rural Only, ___Mixed Urban/Rural, ___Private for Profit, ___Private Non-profit, ___Government/Public

_____No. of Staff _____People Served/Year _____Hours of Service/Client

_____No. of Satellite Offices _____Distance to Farthest Client _____Center-based

NAME(S) OF COUNTY SERVED: _____

_____

FUNDING Source(s):___Federal; ___State; ___County; ___City; ___Private; ___Fee For Service; ___Other

POPULATION Served:

___Under 21 - If yes, →→ ___Infants (0-24 mos.) ___Youths (6-12 yrs.)

___Adults (22-64 yrs.) ___Toddlers (24-36 mos. ___Teens (13-18 yrs.)

___Seniors (65 & older) ___Preschoolers (37 mos.-5 yrs.) ___Young Adults (19-21 yrs.)

Disability-related **SERVICES PROVIDED:** _____

_____

Service **DELIVERY PROCEDURES:**___Outreach, ___Case Management, __ Information/Referral; __Advocacy;

__Training/Consultation; __Technical Assistance __Other, specify:_____

ELIGIBILITY Requirements and/or Restrictions:_____

_____

REFERRAL Policy:_____

_____

Can We Include Your Program in the published Rural Disability Service Network Directory? ___Yes; ___No

COMMENTS (How does your program identify/assess clients? What resources do you utilize? What kinds of outcomes are you looking for? What does 'rural' mean to your program? Your clients? etc.):

_____

"The **best feature** of this program is..."_____

Information provided by:_____ Date:_____

APPENDIX

Etiquette of Consumer Involvement

Tom Seekins, Fabricio Balcazar, and Stephen B. Fawcett
Research and Training Center on Independent Living
The University of Kansas

Consumer groups exist to promote a broad set of values in their communities. Among the many values that consumer involvement groups share are such principles as fairness, equal access, equal opportunity, independence, community integration, social acceptance, safety, dignity, and consumer control.

Issues involve the application of these principles in everyday situations. For example, a policy change can have positive or negative effects on the principle of community integration. The general goals of a group are to support positive changes, prevent negative changes, or develop new ways of enhancing these principles. But the approach you take can significantly influence the degree of success you achieve. This lesson describes 10 guidelines that have led others to successful efforts.

Ten Guidelines for Prudent Advocacy

The type of projects your group chooses will contribute to its reputation in the community. Since your group is likely to address many issues over a long time, its reputation is a key to success. The following guidelines have emerged as characteristic of many successful advocacy organizations. This list is by no means complete, but it may serve as a basis for healthy community involvement.

Accentuate the Positive

Respond to at least as many positive events as negative ones by complimenting positive actions and honoring key figures. Keeping positive is easy, and it will win you friends and build your reputation as being a reasonable group. Constructive involvement can serve as the basis for many successful projects.

Begin by Assuming the Best of Others

Challenging the motivations of others often produces needless resistance. Assuming a negative act is the result of ignorance or inattention (maybe even your own) creates opportunities to teach and learn. A correlary is to give credit freely for beneficial decisions. Acknowledging the wisdom and vision of others who support you is likely to increase their commitment to your goals.

Do Your Homework and Document Everything

If your group takes a position or initiates an action based on an error in fact, you stand a good chance of being very embarrassed. Such embarrassment can damage a hard-won reputation. A significant error in fact can also direct attention away from your issues, no matter how important they are. Thus, the first step in developing a position or a project should always involve confirming your information. In addition, you should document everything you do as well as what others tell you. Documentation protects you from denials and counterchargers.

Take the High Ground

When you take a position on an issue, always highlight the general values or principles you are promoting, such as independence, equal access, well being, dignity, or safety. The importance of these values and principles is hard for anyone to deny. They serve as a firm basis for agreement on general community goals. They help prevent personality conflicts stemming from disagreements over details of solutions. And finally, positive values lend an air of eloquence to your position that will impress almost anyone.

Take a Broad Perspective

Although a consumer group is usually too small to act on every relevant issue, it is wise to spread your attention across different issue types over time. Various issues are likely to share many similarities. A group that focuses only on transportation issues will have a narrow appeal to members and the public. Addressing issues of accessibility broadens appeal and generates more opportunities for involvement. It probably increases opportunities for success, too.

Plan Many Small Successes

Groups are more likely to grow and maintain themselves over time, if they have many successes. One way to facilitate success and growth is to have many small projects rather than one major one. Many successful efforts over time will build the competency and reputation of the group so that it can take advantage of major opportunities more effectively.

Begin With the Simplest Step

If an issue is personally important, members tend to want to make an immediate, strong response. This approach can seriously restrict your options and those of others who support you. Radical actions should usually be saved as options until other, less intrusive alternatives have been tried without success.

Be Prepared to Follow Through

Once you have begun to address an issue, be prepared to follow through. This means you should be ready to compliment responsiveness, attend meetings, compromise, or, escalate your approach, if there is no response. Some situations may become intolerable, and you should not seek to avoid conflict at all cost. If you don't follow through on your current efforts, others will be likely to ignore your future efforts.

Be Reasonable

Developing a quality community requires cooperation and compromise between groups with competing interests. Public support is almost always on the side of those who are most reasonable in their approach and demands. Action that offends interested parties--especially the public--decreases the chances for cooperation and success.

Be Prepared to Accept Success

Success might best be viewed as progress toward an ideal rather than capitulation by the enemy. You should advocate for your own proposals, but you should also keep an open mind for alternatives and compromises offered by others. They, too, have legitimate goals and need some control over their situation. Moreover, their knowledge of the workings of systems you may not understand might lead to greater success than you imagined. A mutually acceptable solution to a problem is a success for everyone. Your willingness to help others win will contribute to a strong group reputation.

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NATIONAL INSTITUTE ON DISABILITY AND REHABILITATION RESEARCH

ADA Technical Assistance Grants and Coordination Contract

The National Institute on Disability and Rehabilitation Research (NIDRR), within the U.S. Department of Education, has awarded 15 grants to provide technical assistance to those with rights and duties under the Americans with Disabilities Act (ADA). This new 4.55 million dollar program establishes: 10 Regional Disability and Business Accommodation Centers; 3 Materials Development Projects; 2 National Training Projects; and 1 national coordination contract.

The Regional Disability and Business Accommodation Centers will be funded for five years and receive approximately $300,000 per year. The Canters will work closely with the business and disability communities to perform four basic functions: (1) disseminate information; (2) provide direct technical assistance; (3) provide referrals for specialized information and technical assistance; and (4) train interested and affected parties.

The Materials Development Projects will be funded for two years and receive approximately $250,000 per year. The Materials Development Projects will address training and technical assistance needs in the areas of employment, public accommodation and accessibility.

The National Training Projects will be funded for three years and receive approximately $250,000 per year. One Training Project will target the Independent Living Center community and the second will address a broader audience of parent and family networks.

NIDRR has also awarded a contract to coordinate the activities of all of its technical assistance grantees. This contract will be funded for three years for approximately $300,000 per year.

For further information contact David Esquith, MES 3424, NIDRR, 330 C Street SW, Washington, DC 20202-2572; telephone (202) 732-5801; TDD (202) 732-5316.

BEST COPY AVAILABLE

ADA TECHNICAL ASSISTANCE CENTERS

REGION I - CT ME MA NH RI VT
University of Southern Maine
Muskie Institute of Public Affairs
Jennifer Eckel, Director
96 Falmouth Street
Portland, ME 04103
(207) 780-4430
(207) 780-4417 FAX

REGION II - NJ NY PR NJ
United Cerebral Palsy Association
Richard Dodds, Director
354 South Broad Street
Trenton, NJ 08608
(609) 392-4004
(609) 392-3505 FAX

REGION III - DE DC MD PA VA WV
Endependence Center of Northern Virginia
Sharon Mistler, Director
2111 Wilson Blvd.
Arlington, VA 22201
(703) 525-3268
(703) 525-6835 FAX

REGION IV - AL FL GA KY MS NC SC TN
United Cerebral Palsy Association
US National Alliance of Business
Shelley Kaplan, Director
1776 Peachtree Road
Atlanta, GA 30309
(404) 888-0022
(404) 888-9091 FAX
(404) 888-9006 TDD

REGION V - IL IN MI MN OH WI
University of Illinois at Chicago
University Affiliated Program
in Developmental Disabilities
David Braddock, Director
1640 West Roosevelt Road
Chicago, IL 60608
(312) 413-1647 V/TDD

REGION VI - AR LA NM OK TX
Independent Living Research Utilization
The Institute for Rehabilitation and Research
Lex Frieden, Director
2323 South Sheperd Blvd., Suite 1000
Houston, TX 77019
(713) 520-0232
(713) 520-5785 FAX
(713) 5520-5136 TDD

REGION VII - IA KS NB MO
University of Missouri at Columbia
Jim DeJong, Director
401 East Locust Street
Columbia, MO 65201
(314) 882-3807
(314) 882-1727 FAX

REGION VIII - CO MT ND SD UT WY
Meeting the Challenge, Inc.
Randy W. Dipner, Director
3630 Sinton Road, Suite 103
Colorado Springs, CO 80907-5072
(719) 444-0252
(719) 444-0269 FAX

REGION IX - AZ CA HI NV PB
Berkeley Planning Associates
Erica Jones, Director
440 Grand Avenue, Suite 500
Oakland, CA 94610
(415) 465-7884
(415) 465-7885 FAX

REGION X - AK ID OR WA
Washington State Governor's Committee
Toby Olson, Director
212 Maple Park KG-11
Olympia, WA 98504
(206) 438-3168
(206) 438-4014 FAX
(206) 438-3167 TDD

ADA MATERIALS DEVELOPMENT PROJECTS

Employment
Cornell University
Susanne Bruyere, Director
120 Day Hall
Ithaca, NY 14853-2801
(607) 255-9536

Employment
International Association of Machinists
Center for Administration Rehabilitation
and Employment Services
Angela Trailforos, Director
1300 Connecticut Avenue, NW - Suite 912
Washington, DC
(202) 857-5173
(202) 728-2969 FAX

Public Accomodation/Accessibility
Barrier Free Environments, Inc.
Ronald L. MaceWater, Director
Garden Highway 70 West
Raleigh, NC 27622
(919) 782-7823 V/TDD
(919) 787-1984

ADA NATIONAL TRAINING PROJECTS

Peer and Family Training Network
Parent Information Center
Judith Raskin, Director
151A Manchester Street
Concord, NH 03301
(603) 224-7005 V/TDD
(603) 224-4365 FAX

Local Capacity-Building for Independent Living
National Council on Independent Living
Anne Marie Hughey, Director
3607 Chapel Road
Newtown Square, PA 19073
(215) 353-0678
(215) 353-6753 FAX
(215) 353-6083 TDD

NATIONAL ADA TECHNICAL ASSISTANCE GRANTS COORDINATOR

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Raymond Glazier, Director
55 Wheeler Street
Cambridge, MA 02138-1168
(617) 492-7100
(617) 492-5219 FAX